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THE KILLING WORDS? HOW THE NEW QUALITY-OF-LIFE ETHIC AFFECTS PEOPLE WITH SEVERE DISABILITIES

Teresa HarveyParedes

THE quality-of-life ethic was traditionally used to measure environmental conditions that either improved or impaired the quality of a person's life. Reformers used this traditional concept to increase the standard of living by improving working conditions, health care, education, and other living conditions.¹ In the wake of the bioethics movement, however, the dynamics of the quality-of-life ethic have been drastically altered. Throughout the last few decades, courts gradually accepted this altered ethic, resulting in tragic consequences for people with severe disabilities. Now, rather than measuring conditions that improve life, the quality-of-life ethic has come to measure the worth of a person's life to herself and those around her, and, according to some ethicists, the very personhood of an individual. Human life is now a relative concept, and personhood — when it begins, what it is, and when it ends — may depend on a quality-of-life determination.

In 1942, the *American Journal of Psychiatry* carried an article written by Foster Kennedy, M.D., president of the Euthanasia Society.² Kennedy called for the involuntary euthanasia of children who, at five years of age, were diagnosed as defective by a medical team. If the team determined the child was "hopelessly unfit" and had "no future or hope of one,"³ then euthanasia was appropriate. Kennedy redefined the children with disabilities to justify his recommendation. No longer were they children, but "hopeless defectives," "nature's mistake[s]," "tortured and convulsed, grotesque and absurd, useless and foolish and entirely undesirable."⁴ Kennedy also rede-

1. See *infra* notes 24-29 and accompanying text for additional discussion of the traditional use of the quality-of-life ethic.

2. Foster Kennedy, *The Problem of Social Control of the Congenital Defective*, 99 AM. J. PSYCHIATRY 13 (1942). The Euthanasia Society was the forerunner of today's Society for the Right to Die. Rita L. Marker et al., *Euthanasia: A Historical Overview*, 2 MD. J. CONTEMP. LEGAL ISSUES 257 (1991). The Euthanasia Society was formed for the purpose of legalizing euthanasia and hoped "eventually to legalize the putting to death of nonvolunteers beyond the help of medical science." Statement of Charles E. Nixdorff, Euthanasia Society Treasurer quoted in 'Mercy' Death Law Proposed in State: Euthanasia Society Drafts Bill to Legalize Painless Killing of Incurables, N.Y. TIMES, Jan. 27, 1939, at 21.

3. Kennedy, *supra* note 2, at 14.

4. *Id.* It is interesting to note that Kennedy argued against euthanasia of people with manic-depressive psychoses, stating that to do so would "make a great happiness for the present and in the second generation; but . . . would produce a population of Babbits, or mediocri-

fined the death of these children with disabilities: Involuntary euthanasia was "a merciful and kindly thing to relieve that defective . . . of the agony of living."⁵ At that time, Kennedy's ideas were considered out of the bioethics mainstream. After the horrors of the Nazi killings were discovered following World War II, his plan had even less public support.⁶

Yet today, fifty years after Kennedy's first call, his echo is heard in the voices of doctors, ethicists and judges, who, using the altered quality-of-life ethic, advocate the "nontreatment" of newborns whose lives are "meaningless"⁷ and the "right to refuse medical treatment"⁸ to adults with physical or mental disabilities. Today, the killing words are dressed in caring terms, compassionately calling for the rights of people with disabilities to "self-determination,"⁹ and to "death with dignity."¹⁰ For children and mentally disabled people who cannot exercise their own "self-determination," substituted judgment, proxy or the right to privacy¹¹ conveniently fills in the gap. A closer look at real-life situations, however, reveals that self-determination is provided only when the court believes the disabled persons *should* die; they are allowed to die only when the courts believe they have no dignity;

ties, capable of pushing but not of leaping; and it's the leap that counts." *Id.* at 13. Additionally, Kennedy opposed euthanasia of people with terminal illness. *Id.* at 15. Euthanasia was appropriate only for mentally disabled people. According to Kennedy, people with a mental age of eight or nine should be institutionalized, sterilized and "taught simple manual work." *Id.* at 13-14. People with mental ages less than eight were candidates for euthanasia. "So the place for euthanasia, [according to Kennedy] is for the completely hopeless defective: nature's mistake; something we hustle out of sight, which should never have been seen at all." *Id.* at 15.

5. *Id.*

6. In the 1920s the debate over eugenics and the right of people with terminal illness to die raged in Germany and ended with tragic consequences in the 1940s. While some scoff at comparisons between Nazi Germany and today, the parallels are ominous. For an in-depth analysis of the similarities between pre-war Germany and the debate as it is currently framed in the United States, see HUGH G. GALLAGHER, *BY TRUST BETRAYED: PATIENTS, PHYSICIANS, AND THE LICENSE TO KILL IN THE THIRD REICH* (1990); Marker et al., *supra* note 2. Following World War II, and revelations of the horrors of Nazi Germany, the United States' eugenics movement receded.

7. See JOSEPH FLETCHER, *HUMANHOOD: ESSAYS IN BIOMEDICAL ETHICS* 140-438 (1979); JEFF LYON, *PLAYING GOD IN THE NURSERY* 237-50 (1985); ROBERT F. WEIR, *SELECTIVE TREATMENT OF HANDICAPPED NEWBORNS: MORAL DILEMMAS IN NEONATAL MEDICINE* 59-89 (1984).

8. See *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).

9. *Id.*

10. Several states have attempted to pass "Death with Dignity" laws. In 1991, Washington citizens rejected Initiative 119, which would have legalized physically-assisted suicide at the request of a mentally competent person who was terminally ill with a life expectancy of less than six months. The initiative narrowly lost: Forty-six percent of the voters supported the bill. '91: *Euthanasia: Right-to-Die Proposal is Rejected: Supporters, Foes Say Debate Will Continue*, ATLANTA J. & CONST., Nov. 6, 1991, at A7. In November 1992, California voters narrowly rejected a similar measure by a 51-46% margin. B.D. Colen, *Euthanasia Issue Lives On*, NEWSDAY, Nov. 10, 1992, at F1. Maine, Oregon, Michigan, and Iowa legislatures have considered the issue of legalizing physician-assisted suicide. Ralph Jimenez, *Legislators Debate Assisted-Suicide Bill*, BOSTON GLOBE, Feb. 7, 1993, at 37. The New Hampshire, Connecticut, and Virginia legislatures are currently considering the issue. *Id.* Proponents of such bills consistently use "death with dignity" rhetoric to justify the proposed laws. *Id.*

11. See ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 98-117 (1990).

and privacy is a curtain behind which society can request the death of one of its members that will have a negative impact on its resources or lifestyle.

How did this happen? How has the bioethics movement come to recharacterize whose life is and whose life is not worth living? How has the right to self-determination been turned on its head to justify nontreatment (death) of people with disabilities, sometimes without regard to their own desires?¹² How have courts redefined severely disabled people as "bodily environments,"¹³ and bioethicists redefined the quality-of-life ethic in terms of maintaining an "acceptable" environment or an "acceptable" use of resources, rather than in terms of improving the quality of people's lives?¹⁴ And, what are the ramifications for the targeted people — those with severe physical or mental disabilities?¹⁵

This Comment will examine how bioethicists and courts are using the quality-of-life ethic to justify the death of people with severe physical or mental disabilities by asserting that their life is not worth living.¹⁶ Part I will explore the range of quality-of-life standards proposed by ethicists to determine appropriate medical treatment.¹⁷ Part II will trace the use of the quality-of-life ethic in the past two decades by courts in "right to die" or "right to refuse medical treatment" cases involving people with severe disabilities.¹⁸ This section will demonstrate that judicial application of the quality-of-life ethic has proved devastating for people with severe disabilities because the inherent biases of the decision-makers invariably render a presumption that death is preferable to life with severe disabilities. Part III will explore how other decision-makers also apply the quality-of-life ethic with detrimental consequences.¹⁹ Part IV will then discuss how uncertain diagnoses and changing, ambiguous definitions often have deadly results for people with disabilities regardless who the decision-maker is.²⁰ Part V will conclude by calling for a reexamination of this nation's attitude toward people with severe disabilities.²¹ We must recognize that inherent societal bias against people with disabilities invariably contaminates the decision-making

12. See *infra* notes 173-183 and accompanying text.

13. *McKay v. Bergstedt*, 801 P.2d 617, 625 (Nev. 1990).

14. See text accompanying *infra*, note 49.

15. While the majority of cases, statutes, regulations, and other sources discussed in this Comment use "handicapped" terminology, this Comment will utilize "disability" and "with disabilities" terminology, which is the preferred language of most disability rights advocates. See Mary Johnson, *Kiss "Wheelchair-Bound" Goodbye*, THE DISABILITY RAG, May-June 1987, at 31. "People first" terminology is also consistent with the language of the Americans with Disabilities Act. This term simply refers to the need to emphasize that people are people regardless of any labels attached to them, and these labels should be only of minimal or no importance in determining a person's right to equal opportunity.

16. The basic issue of a person's right to die or the right to die for people who are terminally ill is beyond the scope of this paper. Instead, the only purpose is to demonstrate that if these rights do or should exist, they apply no more to people with disabilities than to others. For a thorough analysis of the right to die, see Thomas W. Mayo, *Constitutionalizing the Right to Die*, 99 MD. L. REV. 103 (1990).

17. See *infra* notes 24-74 and accompanying text.

18. See *infra* notes 75-186 and accompanying text.

19. See *infra* notes 187-205 and accompanying text.

20. See *infra* notes 206-37 and accompanying text.

21. See *infra* notes 238-45 and accompanying text.

process and justifies nontreatment. We must, therefore, refocus the quality-of-life ethic away from the exclusionary model²² that favors death and back to the model that considers how to improve the *lives* of people with severe disabilities.

I. CURRENT QUALITY-OF-LIFE STANDARDS

*"Thousands of medical ethicists and bioethicists, as they are are called, professionally guide the unthinkable on its passage through the debatable on its way to becoming the justifiable until it is finally established as the unexceptional."*²³

In the United States, the quality-of-life concept was traditionally framed in the context of liberty: The right of every person to life, liberty and the pursuit of happiness.²⁴ Beginning in the late 19th and early 20th century, reformers pushed to equalize opportunity for all citizens.

The ideal of fundamental human equality had caught on. Not only were all humans entitled to liberty but they were also entitled to a minimal level of physical well being and the institutions which could guarantee this. The movement continued to expand so as to not only include basic material goods (food, clothing, shelter health resources) but also social goods: land reform, employment mobility, political participation and franchise, free public education and today it is being extended to recreational and cultural opportunities. . . . The emphasis is upon the minimal necessary conditions and the concern is inherently equalitarian — that is, it stresses the insurance of these minimal goods for all human beings.²⁵

Like other minority populations, people with disabilities were historically denied equal access to the social, economic, and political systems in this country.²⁶ In the past few decades, reformers worked to improve the quality-of-life of people with disabilities by providing for the right to education,²⁷ for deinstitutionalization,²⁸ and most recently, for the passage of the Americans with Disabilities Act of 1990.²⁹

22. See *infra* notes 30-31 and accompanying text.

23. Richard J. Neuhaus, *The Return of Eugenics*, COMMENTARY, Apr. 1988, at 15, 19.

24. William Aiken, *The Quality of Life*, in QUALITY OF LIFE: THE NEW MEDICAL DILEMMA 17, 18 (James J. Walter & Thomas A. Shannon eds., 1990) [hereinafter THE NEW DILEMMA].

25. *Id.* at 19.

26. See Martin H. Gerry & Celzne M. McWhorter, *A Comprehensive Analysis in Federal Statutes and Programs for Persons with Severe Disabilities*, in CRITICAL ISSUES IN THE LIVES OF PEOPLE WITH SEVERE DISABILITIES 495 (Luanna H. Meyer et al. eds., 1991) [hereinafter CRITICAL ISSUES].

27. In 1973, Congress passed the Education for All Handicapped Children Act, Pub. L. No. 94-194, 89 Stat. 773 (1973) (codified as amended at 20 U.S.C. §§ 1400-1485) which established the right of all children to receive an appropriate education.

28. Geraldo Rivera's expose of the horrors of Willowbrook State School, an institution housing 5400 people with mental disabilities, gripped the nation and resulted in a demand for improved living conditions for all people with disabilities. For a comprehensive history of Willowbrook State School, Rivera's exposé and the resulting litigation, see GERALDO RIVERA, WILLOWBROOK: A REPORT ON HOW IT IS AND WHY IT DOESN'T HAVE TO BE THAT WAY (1972); DAVID J. ROTHMAN & SHEILA M. ROTHMAN, THE WILLOWBROOK WARS (1984).

29. Pub. L. No. 101-336, 104 Stat. 327 (codified at 42 U.S.C. §§ 12101-12213 (Supp. II

During the same period, however, a conflicting quality-of-life ethic developed within the medical community and, more recently in the judiciary, around the right to die debate. Under this new ethic,³⁰ quality-of-life justifies active or passive euthanasia of people with severe disabilities. This ethic operates to exclude "some people from the moral community and concomitantly from normal standards of moral treatment. The judgment is made that because a person's 'quality-of-life' is below the desirable level, that person's life is not worth living and we are justified in treating them accordingly."³¹ The following sections explore several expressions of this altered quality-of-life ethic.

A. QUALITY-OF-LIFE BASED ON REDEFINED PERSONHOOD

For more than two decades, Joseph Fletcher has advanced the ethic that not all humans are persons. Fletcher declines to frame his inquiry into the

1990)). The Americans with Disabilities Act is a comprehensive civil rights statute that provides for the "elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(2). Title I prohibits discrimination in all aspects of employment. 42 U.S.C. §§ 12111-12117. Title II prohibits discrimination in all services and programs provided by state and local governments. 42 U.S.C. §§ 12131-12165. Title III prohibits discrimination against individuals with disabilities by public accommodations. 42 U.S.C. §§ 12181-12189. Title IV requires accessible telephone services. 47 U.S.C. §§ 225, 661.

30. References to the quality-of-life ethic in recent history actually began in the mid-nineteenth century in the context of eugenics and the social good. The Industrial Revolution resulted in an increased quality of life for most people, providing improved health care, living standards, and working conditions. GALLAGHER, *supra* note 6, at 74-95. Charles Darwin's *Origin of the Species*, which expounded the "survival of the fittest" theory, however, negatively altered society's perception of people with disabilities. *Id.* Published a few years later, *The Descent of Man*, increased this negative perception. In it, Darwin lamented

We civilised men, on the other hand, do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor laws; and our medical men exert their utmost skill to save the life of everyone to the last moment. . . . Thus the weak members of civilised societies propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man.

CHARLES DARWIN, *THE DESCENT OF MAN AND SELECTION IN RELATION TO SEX* 136 (D. Appleton & Co. ed., 1913) (1871). The eugenics movement grew out of Darwin's theories. Its purpose was to improve and strengthen the human race. "They were out to make a better world. . . . It would be a world in which all people of whatever race or nationality would live just the way the American progressives did." GALLAGHER, *supra* note 6, at 77-78. This goal necessitated that unfit people be prohibited from passing on their unfit conditions; and therefore, the unfit — disabled people and criminals — were prohibited from procreation. *Id.* at 84. In the first two decades of the twentieth century, thirty states passed legislation to permit sterilization of unfit persons. *Id.* at 82-83. This practice was upheld by the Supreme Court in *Buck v. Bell*, 274 U.S. 200 (1927), where Justice Oliver Wendell Holmes held that "[s]ociety can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. . . . Three generations of imbeciles are enough." *Id.* at 207.

By 1923, forty-three states also had legislation authorizing the permanent institutionalization of people with disabilities to protect them and society. The institutions were intended to serve as work farms and colonies where disabled people could live out their lives without harming society and without procreating. GALLAGHER, *supra* note 6, at 84. "The [reform] campaign was full of good intentions, and its tone was as patronizing as a Jerry Lewis telethon: 'It is the thing to do for the feeble minded — get them out of the big world where they have such a hard time because they are not like other folks.'" *Id.* at 85 (quoting MARK H. HALLER, *EUGENICS: HEREDITARIAN ATTITUDES IN AMERICAN THOUGHT* 126 (1963)).

31. Aiken, *supra* note 24, at 20.

right to die (or live) in terms of quality-of-life concepts, declaring instead that if certain qualities do not exist in an "individual of the species *homo sapiens*," then the individual is not a person, and therefore has no right to life.³² Fletcher's personhood checklist contains fifteen characteristics: minimum intelligence,³³ self-awareness,³⁴ self control,³⁵ sense of time,³⁶ sense of futurity,³⁷ sense of the past,³⁸ capacity to relate to others,³⁹ concern for

32. FLETCHER, *supra* note 7, at 12-16. Fletcher holds that "[s]ynthetic concepts such as human . . . and person require operational terms, spelling out the which and what and when." *Id.* at 12. Several other ethicists base nontreatment decisions upon a determination of personhood. Michael Tooley asserts that personhood is "a moral category that denotes the limits of justifiable termination of life. If an entity, regardless of its age or maturity, can meet the requirements of personhood, its life is given moral protection from arbitrary and indiscriminate destruction." See WEIR, *supra* note 7, at 152 (citing Michael Tooley, *A Defense of Abortion and Infanticide*, in *THE PROBLEM OF ABORTION* 51, 53 (Joel Feinberg ed., 1973)). According to Tooley, personhood has five requirements:

A capacity for desires about one's future, a capacity to have a concept of a self, the actuality of being a conscious subject of experiences, a capacity for self-consciousness, and the actuality of being a continuing subject of experiences and other mental states '[I]n order for something to have a right to life it must either now possess, or have possessed at some time in the past' these five properties.

WEIR, *supra* note 7, at 153, (citing Michael Tooley, *Decisions to Terminate Life and the Concept of Person*, in *ETHICAL ISSUES RELATING TO LIFE AND DEATH* 91 (John Ladd ed., 1979)).

Mary Anne Warren asserts five similar requirements for personhood: "consciousness, reasoning ability, self-motivated activity, the capacity to communicate, and the presence of self-awareness." WEIR, *supra* note 7, at 156 (citing Mary Anne Warren, *On the Moral and Legal Status of Abortion*, in *TODAYS MORAL PROBLEMS* 130-31 (Richard Wasserstrom ed., 1975)).

33. FLETCHER, *supra* note 7, at 12. Fletcher requires individuals to grade a 40 on the Stanford-Binet Test in order to be assured of personhood.

Any individual of the species *Homo sapiens* who falls below an I.Q. grade of 40 in a standard Stanford-Binet test, amplified if you like by other tests, is questionably a person; below the mark of 20, not a person Mere biological life, before minimal intelligence is achieved or after it is lost irretrievably, is without personal status. This has bearing, obviously, on decision making in gynecology, obstetrics, and pediatrics, as well as in general surgery and medicine.

Id.

Several other ethicists consider cognitive function to be the benchmark measurement for determining whether the quality of a person's life is inadequate to justify life-sustaining treatment. For example, Dr. Fred Plummer of the Cornell University Medical Center asserts: "I believe that the meaning of life is cognition and self-awareness, not merely visceral survival. The concept holds that when the cognitive brain has departed, the person has departed." Dr. Fred Plummer, *as quoted in* Kathleen Stein, *Last Rites*, OMNI, Sept. 1987, at 58-60. See also *infra* notes 50-59 and accompanying text.

34. FLETCHER, *supra* note 7, at 12-13.

35. *Id.* at 13. Fletcher asserts that if an individual cannot maintain self control and this lack of control cannot be remedied through medical means, the individual is not a person. *Id.* Under this standard, people with severe cerebral palsy or other physical disabilities that are characterized by lack of muscle control are not persons.

36. Fletcher defines this requirement as the sense of the "passage of time." *Id.* at 13.

37. *Id.*

38. *Id.*

39. *Id.* at 14. This characteristic requires that the individual be capable of maintaining interpersonal relationships. "Interpersonal relationships, of the sexual-romantic and friendship kind, are of the great importance for the fullness of what we idealize as being truly personal." *Id.*

others,⁴⁰ capacity to communicate,⁴¹ control of existence,⁴² curiosity,⁴³ changeability,⁴⁴ balance of rationality and feeling,⁴⁵ idiosyncrasy,⁴⁶ and neocortical function.⁴⁷ Fletcher describes an individual who does not meet his criteria as a "human vegetable [that] is progressively degraded while constantly eating up private or public financial resources,"⁴⁸ and asserts that a moral obligation to permit euthanasia exists in such cases.⁴⁹

B. QUALITY-OF-LIFE BASED ON COGNITIVE FUNCTION

Dr. Ronald Cranford asserts that a person diagnosed as permanently unconscious should be declared dead, with no legal rights or liberties.⁵⁰ In an article written with David Randolph Smith, Cranford declared that a person in a vegetative state has no interests in continued existence, lacks personhood and is instead a "creature of modern day medicine."⁵¹ More recently, Cranford asserted that a minimum intellectual capacity beyond consciousness is necessary to retain personhood. He recommends discontinuance of food and water from people with severe brain damage. According to Cranford, their lives lack the requisite quality for personhood. He testified in *Cruzan v. Harmon*⁵² that he has "stopped fluids and nutrition on patients who were conscious and who had some degree of interaction with the environment," because their lives, in his estimation, were not worth living.⁵³

40. *Id.*

41. *Id.* at 14-15.

42. *Id.* at 15. This characteristic seems related to self-control:

It is of the nature of man that he . . . has only finite knowledge, freedom, and initiative, but what he has of it is real and effective. Invincible ignorance and total helplessness are the antitheses of humanness, and to the degree that a man lacks control he is not responsible and to be irresponsible is to be subpersonal. This item in the agenda applies directly, for example, in psychiatric medicine, especially to severe cases of toxic and degenerative psychosis.

Id.

43. *Id.*

44. *Id.*

45. *Id.* at 15-16.

46. *Id.* at 16.

47. *Id.* This requirement is, according to Fletcher, the "cardinal indicator." *Id.* "Before cerebration is in play, or with its end, in the absence of the synthesizing function of the cerebral cortex, the person is nonexistent. Such individuals are objects but not subjects." *Id.* In addition to the fifteen characteristics, Fletcher listed five negative characteristics: "(1) Man is not non- or anti-artificial . . . (2) Man is not essentially parental . . . (3) Man is not essentially sexual . . . (4) Man is not a bundle of rights . . . [and] (5) Man is not a worshipper." *Id.* at 16-18.

48. Joseph Fletcher, *Ethics and Euthanasia*, in *TO LIVE AND LET DIE: WHEN, WHY AND HOW* 119 (1973).

49. *Id.*

50. Ronald Cranford & David R. Smith, *Consciousness: The Most Critical Moral (Constitutional) Standard for Human Personhood*, 13 AM. J. L. & MED. 233, 241, 247 (1987).

51. *Id.* at 247.

52. *Cruzan v. Harmon* (Cir. Ct. Jasper County, Mo. 1988) (No. CV38-9P), cited in *Medical Treatment Rights of Older Persons and Persons with Disabilities: 1991 Developments*, 7 ISSUES IN L. & MED. 417 (1992) [hereinafter *1991 Developments*].

53. Transcript, *Cruzan v. Harmon* (Cir. Ct. Jasper County, Mo. 1988) (No. CV38-9P), cited in *1991 Developments*, *supra* note 52. Cranford asserts that it is unethical to use a respira-

Reverend Richard A. McCormick defines quality-of-life according to the individual's potential to maintain human relationships.⁵⁴ According to McCormick, a person's life has value "only insofar as it contains some potentiality for human relationships."⁵⁵ If this potential is not present or "would be utterly submerged and undeveloped in the mere struggle to survive," medical care is extraordinary and therefore nontreatment is justified.⁵⁶

Nancy Rhoden's theory is consistent with McCormick's. According to Rhoden, a person's quality-of-life is relative to their "ability to participate at least minimally in those experiences that make life recognizably human" as measured by their level of consciousness.⁵⁷ Based on this standard, medical treatment⁵⁸ can be withheld from an individual who "will never be conscious[,] is in unremitting pain[,] will live only with major, highly restrictive technology which is intended to be temporary (e.g., artificial ventilation)," or "lacks potential for human interaction as a result of profound retardation."⁵⁹

Both the personhood requirements and minimum intelligence requirements are dubious because the criteria are too susceptible to inaccuracy. Measuring intelligence requires a minimum level of communication. Many people with severe disabilities have multiple disabilities involving their neural, sensory, and physical functions, which may interfere with their ability to communicate their knowledge and comprehension. All too often, this inability to communicate is translated into a diagnosis of severe mental retardation.⁶⁰ Even without multiple complications, people with severe mental disabilities are especially difficult to accurately assess. Intelligence tests were normed on nondisabled children and require knowledge of information taught in regular elementary schools. Children with severe disabilities have often been excluded from these experiences and therefore denied the oppor-

tor on persons who have severe brain damage with no hope of improvement. AP, *Helga Wanglie, Woman in Right to Life Battle*, CHI. TRIB., July 6, 1991, at C13. Joseph Fletcher also included a minimum intelligence requirement in his personhood list. See *supra* note 33.

54. Richard A. McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229 J. AM. MED. ASS'N. 172, 175 (1974).

55. *Id.*

56. *Id.*

57. Nancy Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1322 (1985).

58. Food and water are included as medical treatment by Rhoden. *Id.* at 1329.

59. *Id.* at 1322-23. Rhoden also asserts that non-treatment is also justified with terminally ill people, or, in the case of newborns, if they will not live past infancy. *Id.* Ruth Russell also endorses this approach: "If one is no longer conscious or able to communicate with others as a human being, one must say he is already socially, psychologically, and spiritually dead. . . . The traditional concept of the sanctity of life must be modified by concern for the quality-of-life." O. RUTH RUSSELL, *FREEDOM TO DIE: MORAL AND LEGAL ASPECTS OF EUTHANASIA* 220 (1977). In *Medical Technology and the Law; IV. Neo-natal Treatment Decisions*, 103 HARV. L. REV. 1584 (1990), symposium members endorsed a standard that combined Rhoden's standard with the 1934 Child Abuse Amendments Regulation's three-tiered approach. See *infra* notes 98-101 for a discussion of the approach taken in the Child Abuse Amendment of 1984.

60. See Ian M. Evans, *Testing and Diagnosis: A Review and Evaluation*, in *CRITICAL ISSUES*, *supra* note 26, 25, 26-27.

tunity to learn the necessary information.⁶¹

The 1989 Academy Award-winning movie *My Left Foot* depicted the true story of Christy Brown, an Irish artist and author who was incorrectly labelled mentally retarded for most of his early life, until he learned to write with his foot.⁶² The best selling book *Nobody Nowhere* is an autobiography of Donna Williams, a woman with autism who was inaccurately labelled deaf, retarded, emotionally disturbed and insane.⁶³ Recent technological advances have vastly improved the ability to communicate for many people with severe disabilities. Through techniques such as facilitated communication, persons labeled severely retarded are proving that they were inaccurately diagnosed. For example, Arthur Wold, a Washington resident, was labeled severely mentally retarded at age four when he could control neither his movements nor his speech. Recently however, at thirty, he has learned to communicate through facilitated communication, and has demonstrated that while he was labeled severely retarded, he taught himself to read and write.⁶⁴ Other technological advances have been made enabling people with severe disabilities to communicate,⁶⁵ which make reliance on communication ability highly suspect. There are many more accounts of other inaccurate diagnoses — diagnoses which, according to Fletcher's analysis, would have justified terminating lives and which were usually based on an inability to communicate through normal methods. The lives of Wold, Brown, Williams, and countless other people with similar histories should call into doubt any reliance on mental ability or intelligence because they prove that many people labelled severely retarded are, in fact, merely unable to communicate through traditional methods.

C. QUALITY-OF-LIFE BASED ON HOME AND SOCIETAL CONTRIBUTION

The most formulaic standard for determining a minimum quality of life,

61. *Id.* Several well documented studies have demonstrated that many children have been inaccurately labelled mentally retarded due to linguistic or cultural factors that limited their knowledge of the test information. *Id.* at 27.

62. *MY LEFT FOOT* (Mirama Films 1989). Mr. Brown has cerebral palsy.

63. DONNA WILLIAMS, *NOBODY NOWHERE: THE EXTRAORDINARY AUTOBIOGRAPHY OF AN AUTISTIC* 1992. Her autobiography is the first published first-person account of how a person with autism experiences life.

64. Wold is now labeled autistic. See Hank Whittmore, *He Broke the Silence*, *PARADE*, Sept. 20, 1992, at 8-9. Facilitated communication is a process by which a facilitator assists a disabled person in typing on a keyboard, by supporting the person's hand, wrist, or arm. This technique has also been successfully used to help people with autism, cerebral palsy, and Down's syndrome communicate. *Id.*

65. See, e.g., Sandra Friedland, *Computer Helps the Voiceless Speak*, *N.Y. TIMES*, Aug. 16, 1992, at NJ6 (discussing laptop computers equipped with voice synthesizers which enable severely disabled children to communicate); Rose Kim, *The Magic Touch: Keyboard Technique Helps Severely Disabled Students Learn to Communicate*, *L.A. TIMES*, June 17, 1992 (discussing use of computer and facilitated communication for children with autism and other speech disabilities); Randy Pausch & Ronald D. Williams, *Giving CANDY to Children: User-Tailored Gesture Input Driving and Articulator-Based Speech Synthesizer: Communication Assistance to Negate Disabilities in Youth*, *Communications of ACM*, May 1992, available on LEXIS, Nexis Library, Omni File (describing ten-year project to design speech synthesizer to children with severe disabilities).

$QL = NE \times (H + S)$,⁶⁶ was concocted by Anthony Shaw⁶⁷ and utilized by a team of doctors at Oklahoma Children's Memorial Hospital in 1978 to make treatment decisions for children born with spina bifida.⁶⁸ The stated purpose of the formula was to assist doctors in determining which babies born with spina bifida to treat,⁶⁹ and which to let die.⁷⁰ The treatment decisions were based on a prognosis of the newborn's future quality-of-life.⁷¹ When

66. According to this formula, QL represents quality-of-life; NE represents natural endowments, H represents home and family and S represents society. See Anthony Shaw, *Defining the Quality of Life*, 7 THE HASTINGS CENT. REP. 11 (1977), reprinted in THE NEW MEDICAL DILEMMA, *supra* note 24, at 91.

67. *Id.*

68. Richard H. Gross et al., *Early Management and Decision Making for the Treatment of Myelomeningocele*, 72 PEDIATRIC 450 (1983) [hereinafter *Early Management*]. Spina Bifida, or Myelomeningocele, is a condition where cerebrospinal fluid and nerve roots are located outside a child's body in a sac. Nerves located below the sac are damaged to some extent, so the location of the sac is a main factor in the level of physical disability the child will have. Children with spina bifida sometimes also have hydrocephalus, a condition where excessive cerebral spinal fluid collects in the skull. Prompt medical treatment is necessary to prevent skull deformities and brain damage. Sharon M. Paulus, *Suit Filed in Oklahoma Alleging Twenty Four Infants Died after Being Denied Beneficial Medical Treatment*, 1 ISSUES L. & MED. 321 (1986). While treatment is necessary to prevent increasing severity of the disability, "[b]abies considered to have a poor prognosis [of quality of life] have a survival equal to that of babies with a good prognosis, if they receive early surgical treatment." Richard H. Gross, *Newborns with Myelodysplasia - The Rest of the Story*, 313 NEW ENG. J. MED. 1632, 1633 (1985) [hereinafter Gross, *Newborns*].

69. Children chosen for treatment would receive the medically indicated treatment which usually consisted of an operation to close the sac to prevent infection and further damage. When hydrocephalus is also present, medical treatment for this condition typically requires the implantation of a shunt into the skull to drain the fluid. Paulus, *supra* note 68, at 321.

70. Children chosen to die would receive "supportive care," a euphemism for no care. Supportive care consisted of making the child "comfortable" but did not include antibiotic or sedative administration. *Early Management*, *supra* note 68, at 452. Of the thirty-three babies selected for nontreatment, five families requested treatment against the team's recommendation. Two other babies were treated, but long after the initial decision not to treat was made. *Id.* at 453. Carlton Johnson, born in 1982 with several disabilities including spina bifida and hydrocephalus, was one of the children selected for nontreatment. The team diagnosed him as "not a good baby," and recommended nontreatment. Carlton's mother was informed that Carlton would "live six months without [treatment], and then with it, a year." Paulus, *supra* note 68, at 325. Based on this information, she did not request the medically indicated treatment and Carlton was sent to another facility for maintenance until death. One month after his birth, Carlton was transferred back to Children's Memorial Hospital with severe respiratory distress, apnea, ear infection and dehydration. The doctors ordered that no tests or treatment were to be given except suctioning to clear his airway and oxygen and cardiac compressions as needed. In spite of this nontreatment, Carlton survived and was sent back to the nursing facility. Sixteen months later, when it became obvious that he was not going to die, Carlton received the appropriate surgery. However, the surgery could not correct the enlargement of his head and the potential loss of intellectual and physical capabilities due to the delayed surgery. The level of increased disability Carlton will have due to the long delay in treatment remains to be seen. *Id.* at 325-26. The doctors did not recommend treatment for thirty-three infants. If the family, however, requested treatment against the recommendation of the team, the child would be treated. *Early Management*, *supra* note 68, at 453. Following the publication of the experiment, families of several children filed a lawsuit alleging that twenty-four infants died after being discriminatorily denied beneficial medical treatment at the Oklahoma Children's Memorial Hospital, but were unsuccessful. Paulus, *supra* note 68, at 321. See *Johnson by Johnson v. Gross*, 125 F.R.D. 169 (W.D. Okla. 1989), *aff'd* 971 F.2d 1487 (10th Cir. 1992), *cert. denied*, 61 U.S.L.W. 3371 (1993).

71. The doctors acknowledged that infants, who had a poor quality of life prognosis had a survival rate "equal to that of babies with a good prognosis, if they receive early surgical treatment." Gross, *Newborns*, *supra* note 68, at 1633.

the hospital received notice of a child born with spina bifida, a ten-member team⁷² convened and pursuant to the formula, conducted various diagnostic tests on the infant to determine his physical and intellectual capacity (NE). The team then attempted to ascertain the economic and intellectual resources of his family (H), the family's physical proximity to an appropriate medical facility and any governmental agency commitment to provide financial resources for the child's life care (S).⁷³ Based on this evaluation, the team made a treatment recommendation to the family.⁷⁴

II. THE COURTS AND THE QUALITY-OF-LIFE ETHIC

A. PRE-BIRTH

*The appeal of the March of Dimes is 'Help Us to Prevent Birth Defects,' but the way to prevent them is to prevent the birth of defective children.*⁷⁵

Although the Supreme Court recently narrowed *Roe v. Wade*,⁷⁶ abortion of a fetus with disabilities remains legal.⁷⁷ In some states, this right justifies damage awards against doctors who fail to provide the mother with an opportunity to abort a disabled fetus through so called "wrongful birth" or "wrongful life" claims.⁷⁸ A wrongful birth claim⁷⁹ is brought on behalf of

72. The team consisted of a physician's assistant, pediatrician, orthopedist, neurosurgeon, urologist, nurse clinician, social worker, physical therapist, occupational therapist and a psychologist. *Id.*

73. See *Early Management*, *supra* note 68, at 456. In *Medical Technology and the Law: IV. Neo-natal Treatment Decisions*, *supra* note 59, at 1605, symposium members agreed that financial and emotional resource constraints as a valid criteria. "[T]he availability of expert and loving long-term care is inextricably bound up with the quality-of-life prediction for a seriously disabled infant." *Id.* Parents should be given broad decision-making discretion when the child's prognosis is unclear provided they receive medical consultation. *Id.* at 1608. According to members, physicians should be given discretion to choose among treatment alternatives and the judiciary "should allow for a reasonable margin of error in post hoc review" of these decisions. *Id.*

74. See *Early Management*, *supra* note 68, at 452. The doctors reported that sixty-nine infants were included in their study. They recommended thirty-six infants for treatment.

75. FLETCHER, *supra* note 7, at 113.

76. 410 U.S. 113 (1973).

77. See *Planned Parenthood v. Casey*, 112 S. Ct. 2791 (1992) (overruling the *Roe* trimester framework and adopting an undue burden analysis for abortion legislation by upholding the fundamental right to abortion). Just as this paper is not intended to address the general issue of a person's right to die, so too it is not meant to address the basic issue of a woman's right to make private reproductive decisions. Rather, it is intended to address the ramifications of this right as it is applied to fetuses with disabilities, to demonstrate that the quality-of-life ethic is being applied before as well as after birth.

78. See, e.g., *Harbeson v. Park-Davis, Inc.*, 656 P.2d 483, 491 (Wash. 1983) (holding that "parents may avoid the birth of the defective child by aborting the fetus. The difficult moral choice is theirs." (citing *Roe v. Wade*, 410 U.S. 113 (1973))).

79. At least twenty states recognize a cause of action for wrongful birth. See ME. REV. STAT. ANN. tit. 24 § 2931 (West 1990); 42 PA. CONS. STAT. ANN. § 8305(a) (1992 Supp.); *Robak v. United States*, 638 F.2d 471 (7th Cir. 1981) (applying Alabama Law); *Andalon v. Superior Court*, 208 Cal. Rptr. 899 (1984); *Haymon v. Wilkerson*, 535 A.2d 880 (D.C. 1987); *Kush v. Lloyd*, 1992 Fla. LEXIS 2017 (Fla. Dec. 3, 1992); *Moores v. Lucas*, 405 So. 2d 1022 (Fla. Dist. Ct. App. 1981); *Blake v. Cruz*, 698 P.2d 313 (Idaho 1984); *Siemieniec v. Lutheran Gen. Hosp.* 1512 N.E.2d 691 (Ill. 1987); *Pines v. Moreno*, 569 So. 2d 203 (La. Ct. App. 1990); *Proffitt v. Bartolo*, 412 N.W.2d 232 (Mich. Ct. App. 1987), *appeal denied*, 420 Mich. 860 (1988); *Smith v. Cote*, 513 A.2d 341 (N.H. 1986); *Hummei v. Reiss*, 608 A.2d 1341 (N.J. 1991); *Becker v. Schwartz*, 386 N.E.2d 807 (N.Y. 1978); *Galigher v. Duke Univ.*, 638 F. Supp.

the mother or father, alleging that the "negligent advice or treatment deprived them of the choice of avoiding conception or . . . terminating the pregnancy."⁸⁰ A wrongful life claim⁸¹ is brought on behalf of the disabled child, alleging that the child's quality-of-life is such that the fact that she was born is an injury for which damages are recoverable, and "but for the defendant doctor's negligent advice to or treatment of its parents, [she] would not have been born."⁸² In order for a plaintiff to prevail on a wrongful life action, the court determines that "the fetal [child] had an interest in avoiding her own birth, that it would have been best for [the child] if she had not been born."⁸³ Courts insist that recognizing wrongful life actions in no way diminishes the value of disabled children's lives. Nevertheless, it cannot be denied that these cases require a jury to determine that the quality of the disabled child's life is so poor that it would be better if she had been aborted before birth. In *Turpin v. Sortini*, for example, referring to children with severe disabilities, the court held that "[c]onsidering the short life span many of these children and their frequently very limited ability to perceive or enjoy the benefits of life, we cannot assert with confidence that in every situation there would be societal consensus that life is preferable to never having been born at all."⁸⁴

979 (M.D.N.C. 1986), *aff'd in part, vacated in part*, 852 F.2d 773 (4th Cir. 1988) (applying North Carolina law); *Phillips v. United States*, 508 F. Supp. 544 (D.S.C. 1981) (applying South Carolina law); *Jacobs v. Theimer*, 519 S.W.2d 846 (Tex. 1975); *Naccash v. Burger*, 290 S.E.2d 825 (Va. 1982); *Harbeson v. Parke-Davis, Inc.* 656 P.2d 483 (Wash. 1983); *James G. v. Caserta*, 332 S.E.2d 872 (W. Va. 1985); *Dumer v. St. Michael's Hosp.*, 233 N.W.2d 372 (Wis. 1975).

At least three states have refused to recognize wrongful birth statutes. See *Assolino v. Dingfelder*, 337 S.E.2d 528 (N.C. 1985), *cert. denied*, 479 U.S. 835, (1986); *Atlanta Obstetrics & Gynecology Group v. Abelson*, 398 S.E.2d 557 (Ga. 1990); *Wilson v. Kuenzi*, 751 S.W.2d 751 (Mo.), *cert. denied*, 488 U.S. 893 (1988).

80. *Procanik v. Cilio*, 478 A.2d 753, 760 (N.J. 1934).

81. Three states recognize some form of wrongful life claim. See *Turpin v. Sortini*, 643 P.2d 954 (Cal. 1982), *Procanik v. Cillo*, 478 A.2d 755 (N.J. 1984), *Harbeson v. Parke-Davis*, 656 P.2d 483 (Wash. 1982). Wrongful life claims have been rejected in at least twenty-one states. See *Elliott v. Brown*, 361 So. 2d 546 (Ala. 1978); *Pizano v. Mart*, 790 P.2d 735 (Ariz. 1990); *Walker by Lininger v. Eisenbaum*, 764 P.2d 1202 (Colo. 1988); *DiNatale v. Lieberman*, 409 So. 2d 512 (Fla. Dist. App. 1982); *Blake v. Cruz*, 698 P.2d 315 (Idaho 1984); *Siemieniec v. Lutheran General Hospital*, 512 N.E.2d 691 (Ill. 1987); *Bruggeman v. Schimke*, 718 P.2d 635 (Kan. 1986); *Reed v. Campagnolo*, 1993 U.S. Dist. LEXIS 245 (D.C. Md. 1993); *Viccaro v. Milunski*, 551 N.E.2d 7 (Mass. 1990), *Proffitt v. Bartolo*, 412 N.W.2d 232 (Mich. App. 1987), *app. denied*, 430 Mich. 860 (1988); *Wilson v. Jienzi*, 751 S.W.2d 741 (Mo. 1988); *Azzolino v. Dingfelder*, 337 S.W.2d 528 (N.C. 1985), *cert. denied*, 479 U.S. 835 (1986); *Smith v. Cote*, 513 A.2d 341 (N.H. 1986); *Berman v. Allan*, 404 A.2d 8 (N.J. 1979); *Becker v. Schwart*, 386 N.E.2d 806 (N.Y. 1978); *Ellis v. Sherman*, 515 A.2d 1327 (Pa. 1986); *Phillips v. United States*, 508 F. Supp. 537 (D.S.C. 1980); *Nelson v. Krusen*, 678 S.W.2d 918 (Tex. 1984); *James G. v. Caserta*, 332 S.E.2d 872 (W. Va. 1984); *Dumer v. St. Michael's Hosp.*, 233 N.W.2d 372 (Wis. 1975); *Beardsley v. Wierdsma*, 650 P.2d 288 (Wyo. 1982).

82. *Procanik v. Cillo*, 478 A.2d at 760.

83. *Smith v. Cote*, 513 A.2d 341, 352 (N.H. 1986). The court refused to recognize the wrongful life claim. *Id.* at 358.

84. *Turpin*, 643 P.2d at 962-63. The court cited *Curlender v. Bio-Sciences Laboratories*, 165 Cal. Rptr. 477 (Cal. Ct. App. 1980) as an example of when death might be preferable to being born. In *Curlender*, the child had Tay-Sachs disease. According to evidence, the child suffered from "mental retardation, susceptibility to other diseases, convulsions, sluggishness, apathy, failure to fix objects with her eyes, inability to take an interest in her surroundings, loss

One court intimated that a wrongful life theory could be applied against the parents who know that their fetal child has disabilities and decide nevertheless to carry the child to term. According to *Curlender v. Bio-Science Laboratories*,⁸⁵ the parents could be held liable "for the pain, suffering, and misery which they have wrought upon their offspring."⁸⁶ While this is currently a minority position⁸⁷ and has not yet been applied in any other reported case, there are several indications that compulsory abortion is gaining acceptance in the medical community.⁸⁸ For example, Joseph Fletcher makes the following argument for compulsory abortion of fetuses with disabilities:

We protect battered children after birth; why not before? Could we call a knowing conception of a diseased baby "battery"? It is clearly an injury. . . .

. . . .
 . . . [W]e are not morally obligated to have children; no law requires it. . . . If we do have them, however, we are morally obliged to have the healthiest children possible, and actually ought not to have children if we know they are genetically doomed to grievous suffering. . . .

. . . .
 . . . The conclusion here is that (1) having genetic information, we ought to set a minimum quality standard of human health and potential, for selective reproduction; (2) we ought not to bring children into the world if they will fall below the minimum standard; and (3) this minimum standard ought to be backed up by law.⁸⁹

At a recent symposium, participants predicted that public policy will soon mandate genetic screening for all pregnant women to encourage abortions of

of motor reactions, inability to sit up or hold her head up, loss of weight, muscle atrophy, blindness, pseudobulbar palsy, inability to feed orally, decerebrate rigidity and gross physical deformity." *Id.* at 480.

85. 165 Cal. Rptr. 477 (Cal. Ct. App. 1980).

86. *Id.* at 488.

87. The California legislature responded to *Curlender* by passing CAL. CIV. CODE § 43.6 (West 1992), which "relieves the parents of any liability in this situation and also provides that the parents' decision shall neither be 'a defense in any action against a third party' nor 'be considered in awarding damages in any such action.'" *Turpin*, 643 P.2d at 959. The statute states:

- (a) No cause of action arises against a parent of a child based upon the claim that the child should not have been conceived or, if conceived, should not have been allowed to have been born alive.
- (b) The failure or refusal of a parent to prevent the live birth of his or her child shall not be a defense in any action against a third party, nor shall the failure or refusal be considered in awarding damages in any such action.
- (c) As used in this section 'conceived' means the fertilization of a human ovum by a human sperm.

CAL. CIV. CODE § 43.6 (West 1993). Courts have, however, upheld limitations on the "right to bear or beget children with an inherited tendency to mental deficiency." *In re Cavitt*, 157 N.W.2d 171, 175 (Neb. 1968).

88. See, e.g., Bentley Blass, *Human Heredity and Ethical Problems*, 15 PERSP. IN BIOLOGY & MED. 252, 252 (1972) ("Should not the abortion of a seriously defective fetus be obligatory?").

89. FLETCHER, *supra* note 7, at 123-24. Fletcher lists retinoblastoma, Tay-Sachs disease and Down's syndrome as examples of conditions that would justify prevention of birth. *Id.* at 122.

fetuses diagnosed with a disability because "[p]eople *do not have a right* to impose those costs on others by . . . bearing a child that will need financial support from society for its care."⁹⁰ Theresa Morelli⁹¹ asserts that some insurance companies are already adopting compulsory abortion policies. According to Morelli, there are at least two documented cases of insurance companies requiring abortions of fetuses with disabilities. In one case, the fetus had cystic fibrosis, and in another the fetus was diagnosed with adult-onset polycystic kidney disease. "The HMO said, 'If you carry the fetus to term, we will not pay the child's medical expenses or for your pregnancy.'"⁹²

B. INFANTS & CHILDREN

The move to eliminate congenital defects by eliminating the person with the defect has not been limited to the pre-birth arena;⁹³ it has been extended to infants and children as well. Joseph Fletcher not only advocates compulsory abortions to eliminate fetuses with disabilities, he supports active euthanasia, which he characterizes as "postnatal abortion,"⁹⁴ to eliminate what he terms "sub-human" life — infants with severe disabilities.⁹⁵ The now-famous Baby Doe case illustrates another subjective use of the quality-of-life concept with regard to infants. Baby Doe was born in April 1982 to an Indiana couple. He had a malformed esophagus that prevented digestion of food, a condition which was life-threatening but correctable. He also had Down's syndrome,⁹⁶ and the parents, believing he could not live a meaning-

90. Lori B. Andrews, *The Randolph W. Thrower Symposium: Genetics and the Law*, 39 EMORY L.J. 619, 626 (1990) (citing John A. Robertson, *Procreative Liberty and Human Genetics*, 39 EMORY L.J. 697 (1990) (emphasis added)). The controversy surrounding Bree Walker Lampley's second pregnancy further illustrates this trend in the general culture. Mrs. Lampley is a news anchor for a Los Angeles television station. In 1991, her pregnancy was the subject of a Los Angeles talk show. After stating that Mrs. Lampley had a condition which caused hand and feet deformities, talk show host Jane Norris posed the evening topic of debate as follows: "[T]he disease is very possibly going to be passed along to the child that she's about to have. And our discussion this evening will be, is that a fair thing to do? Is it fair to pass along a genetically disfiguring disease to your child?" Jay Matthews, *The Debate Over Her Baby; Bree Walker Lampley Has a Deformity. Some People Think She Shouldn't Have Kids*, WASH. POST, Oct. 20, 1991, at F1.

91. Morelli is a member of the Human Genetics Committee of the Counsel for Responsible Genetics. Vicki Quade, *Protecting the Essence of Being*, HUM. RTS., Winter 1993, at 14.

92. *Id.* at 15.

93. As many commentators have pointed out, disparate treatment of people with disabilities has been expressed since the beginning of history. For a historical overview of infanticide, see WEIR, *supra* note 7, at 3-28.

94. FLETCHER, *supra* note 7 at 144.

95. *Id.* at 140-48.

96. Baby Doe was diagnosed with esophageal atresia and tracheoesophageal fistula. See Anthony Shaw, *Baby Doe and Me*, in COMPELLED COMPASSION: GOVERNMENT INTERVENTION IN THE TREATMENT OF CRITICALLY ILL NEWBORNS 185, 193-94 (Arthur L. Caplan et al. eds., 1992). For a comprehensive history of the Baby Doe Case and resulting federal legislation, see LYON, *supra* note 7, at 21-58 and Phoebe A. Haddon, *Baby Doe Cases: Compromise and Moral Dilemma*, 34 EMORY L.J. 545 (1985). As early as 1973, Doctors Raymond Duff and A.J.M. Campbell focused national attention on the issue of quality-of-life considerations in treatment decisionmaking for newborns. The doctors revealed that in the previous two years, forty-three newborns had died under their "care" after the doctors determined that the newborns' prognosis for an acceptable quality-of-life was poor due to the presence of congeni-

ful life, decided not to consent to the necessary medical treatment. Doctors at the hospital went to court to request judicial approval of nontreatment, but the legal issues were rendered moot when Baby Doe died.⁹⁷

The case received national attention however. As a result, the Child Abuse Amendments of 1984⁹⁸ and subsequent regulations⁹⁹ were enacted, which conditioned federal grants for state child protective services on state prohibitions against withholding medical treatment from disabled newborns. The regulations rejected a quality-of-life rationale, and established a standard which limited nontreatment of infants with disabilities to the following situations:

- (A) the infant is chronically and irreversibly comatose;
- (B) the provision of such treatment would—
 - (i) merely prolong dying;
 - (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or
 - (iii) otherwise be futile in terms of the survival of the infant; or
- (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.¹⁰⁰

While the enforcement provisions have been criticized by some members of the medical and legal community,¹⁰¹ the statutory standard offers a viable

tal disorders. Raymond Duff & A.J.M. Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890, 891 (1973). The doctors withheld medical treatment so the infants would die rather than face lives devoid of "meaningful humanhood." In their report, the doctors called for a move to legitimize such selective treatment. *Id.* at 892, 894.

97. Shaw, *supra* note 96, at 193-94.

98. Child Abuse Amendments of 1984, Pub. L. No. 98-457 (codified as amended at 42 U.S.C.A. §§ 5101-5106(h) (West Supp. 1992)).

99. See 50 Fed. Reg. 14877 (1985) (codified at 45 C.F.R. § 1340.15).

100. 45 U.S.C.A. § 5106g. The medical utility debate was illustrated in the Baby L case. Baby L was born four weeks premature. Although she weighed more than four pounds, there were grave complications, including severe neurological damage. She was resuscitated and stabilized but required several surgeries in the first few months of her life, including a gastrotomy, a Nissen fundoplication and a tracheostomy. John J. Paris et al., *Physicians' Refusal of Requested Treatment: The Case of Baby L*, 322 NEW ENG. J. OF MED. 1012, 1012-13 (1990). Baby L was discharged from the hospital fourteen months later, she required twenty-four hour nursing care. Throughout the next two years, she was repeatedly readmitted for complications, including pneumonia and cardiac arrest. When Baby L was two, her doctors and the hospital determined that it was in her best interest not to receive any additional medical intervention and therefore she should no longer be treated. The mother, however, demanded that Baby L receive all available medical intervention; therefore, a hearing in probate court was required.

In court, the doctors asserted that "since the physicians and hospital believed it would violate their ethical obligation to the patient [to continue medical treatment], they would decline to participate in [further mechanical ventilation]. *Id.* at 1013. When this case was reported in *The New England Journal of Medicine*, the authors asserted that "the refusal was based on the team's assessment that unless a reversal or amelioration of the underlying condition would be expected, painful interventions would be futile and inhumane." *Id.* Although the case was dropped when a physician from another facility agreed to treat Baby L, the case raised the debate over when life becomes unbearable, rendering medical treatment futile, and who is the most appropriate decision-maker to determine this.

101. See, e.g., Stephen A. Newman, *Baby Doe, Congress and the States: Challenging the Federal Treatment Standard for Impaired Infants*, 15 AM. J.L. & MED. 1 (1989) (challenging state authority to promulgate rules under federal statutes as unconstitutional); Kate H. Lind,

alternative to the current quality-of-life ethic when making treatment decisions for newborns with severe disabilities.

The story of Phillip Becker illustrates that nontreatment decisions based on disability continue after infancy. Phillip was twelve-years-old when his public legal battle began in 1979.¹⁰² Phillip was a member of a Boy Scout troop and lived in a board-and-care facility where he had resided since birth. He had Down's syndrome.¹⁰³ He also had a congenital heart defect, common among individuals with Down's syndrome, which required surgery.¹⁰⁴

After repeated unsuccessful attempts to obtain parental consent for the surgery, the state brought suit to obtain judicial approval for the operation. During the initial trial, when asked whether he believed Phillip, "would be better off dead than alive," Phillip's father, Warren Becker, replied: "Yes, I think it would be best for everyone."¹⁰⁵ The Beckers also had Dr. Harry B. Hartzell, pediatrician, testify that

"[b]y his simple and innocent nature, he [Phillip] would be a natural victim to anyone in the community who might take advantage of him by his trust or by taking his money. . . . It is difficult for these individuals to fit into modern urban society and, in my experience, they are isolated and rejected." . . . The decision of the parents was "completely justified," because it was not worth increasing the expectancy "of a life I consider devoid of those qualities which give it human dignity."¹⁰⁶

Although medical testimony indicated that the surgery would most likely prolong Phillip's life and failure to perform the surgery would result in progressive deterioration of Phillip's heart,¹⁰⁷ the Santa Clara County Juvenile Court characterized the operation as "elective" and upheld the parents' denial of treatment.¹⁰⁸ This decision was overturned,¹⁰⁹ but the Beckers successfully fought state officials all the way to the U.S. Supreme Court in an effort to prevent the surgery.¹¹⁰

In 1981, however, the Heath family, who had developed a long-term relationship with Phillip, intervened and requested custody of Phillip, in order to consent to the necessary surgery.¹¹¹ After a twelve-day trial, the court

Note, *Medical Treatment Decision-making for Seriously Handicapped Infants: Is There a Role for the Federal Government?*, 24 B.C. L. REV. 714 (1988) (discussing changing role of federal government in medical treatment decisions); Steven R. Smith, *Disabled Newborns and the Federal Child Abuse Amendments: Tenuous Protection*, 37 HASTINGS L.J. 765 (1986) (criticizing federal statute and regulations as inadequate to sufficiently influence decision making).

102. *In re Philip B.*, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 49 (1980); Pamela Abramson, *Who Speaks for the Child?*, NEWSWEEK, Sept. 3, 1979, at 49.

103. *Id.*

104. *Id.*; see *In re Phillip B.*, 156 Cal. Rptr. at 49.

105. See Abramson, *supra* note 102.

106. Lou Cannon, *A New "Right-to-Life" Battleground Opens Over Mentally Retarded Child*, WASH. POST, July 15, 1979, at A3 (alteration in original).

107. *Id.*

108. See Abramson, *supra* note 102.

109. *In re Phillip B.*, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 49.

110. *Id.* *A Life Worth Living*, UPI, August 8, 1981, available in LEXIS, Nexis Library, UPI File.

111. See *Herbert & Patsy H. v. Warren B.*, 188 Cal. Rptr. 781 (1980); see also *Parents Bar Surgery and Lose Son's Custody*, UPI, Aug. 9, 1981, available in LEXIS, Nexis Library, UPI File. Herbert and Patsy Heath met Phillip in 1972 while volunteering at his board and care

found that the Heath family should be permitted to consent to the surgery,¹¹² declaring that they were Phillip's "psychological parents."¹¹³ The Beckers unsuccessfully appealed the court's decision. The families settled in 1983, however, and Phillip finally received the necessary surgery.¹¹⁴

The previous narrative was intended to highlight the real-life effect of quality-of-life determinations on newborns and children with disabilities. The infants and children discussed were not brain dead, were not in a persistent vegetative state, and were not in a coma. Instead they had disabilities of varying degrees. Their stories demonstrate that quality-of-life formulas and predictions are, in reality, justifications to deny medically indicated treatment for children considered unworthy of life.

C. ADULTS WITH DISABILITIES

In the late 1960s and early 1970s, Representative Walker Sackett, M.D., introduced several "Death with Dignity" bills in the Florida state legislature.¹¹⁵ These bills permitted discontinuing medical treatment of a patient if the treatment was designed "solely to sustain life."¹¹⁶ Sackett proposed to apply the bills to euthanize ninety-percent of the state's institutionalized residents, "primarily on the ground that they lead meaningless lives."¹¹⁷

facility and had maintained a relationship with him through the years. Spencer Sherman, *Court Asked to Halt Surgery on Retarded Child*, UPI, Aug. 31, 1981, available in LEXIS, Nexis Library, UPI File. They provided him tutors, enrolled him in Boy Scouts, and invited him home for weekends. UPI, *Parents Bar Surgery and Lose Son's Custody*, N.Y. TIMES, Aug. 9, 1981 at 21.

112. *Herbert & Patsy H. v. Warren B.*, 188 Cal. Rptr. at 783. The court characterized the Heaths as Phillip's "psychological parents", noting their long-term relationship with Phillip as well as their desire to adopt him. The court also noted that Phillip "suffered harm by the parenting of the Beckers" and that he could "never receive any benefit from custody with the Beckers because they have no expectations for him and will therefore do nothing to allow him to win a place in our society." *Id.*; see George Will, *A Trip Towards Death*, NEWSWEEK, Aug. 31, 1981, at 72.

113. The Beckers, however, successfully appealed to the state supreme court, which again halted the proceedings and necessary surgery. On appeal, the state court of appeals affirmed the lower court holding permitting consent without ruling on whether custody was properly granted. See *Foster Parents Granted Decision Making Power Over Retarded Boy*, UPI, Oct. 20, 1981, available in LEXIS. Nexis Library, UPI File. In early 1983, the state court of appeals officially granted custody to the Heaths and the Becker's appeal to the supreme court was subsequently turned aside. UPI, Apr. 28, 1983, available in LEXIS, Nexis Library, UPI file. The families then settled privately. See Robert Lindsey, *Surgery Follows Pact on Custody: Down's Syndrome Boy's Case Strengthens Rights of Handicapped*, N.Y. TIMES, Oct. 10, 1983, at 1.

114. *Id.*

115. See DEREK HUMPHREY & ANN WICKETT, *THE RIGHT TO DIE: UNDERSTANDING EUTHANASIA*, 88, 95 (1990).

116. See *Doctors Divided Over Euthanasia; Physicians Testify Before Senate Panel on Aging*, N.Y. TIMES Aug. 8, 1972, at 15.

117. These bills would have directed euthanasia of approximately 1500 institutionalized residents. See Evelyn W. Lusthaus, *Involuntary Euthanasia and Current Attempts to Define Persons with Mental Retardation as Less Than Human*, 25 MENTAL RETARDATION 148, 152 (1985). According to the National Institute on Mental Retardation, twenty-nine other states were considering bills at that time which would have legalized euthanasia of children and adults with mental retardation. NAT'L INST. ON MENTAL RETARDATION, *ORIENTATION MANUAL ON MENTAL RETARDATION* (Toronto, Canada 1981), cited in Lusthaus, *supra* at 152.

Fortunately, the bill did not become law. An examination into recent court cases, however, reveals a growing number of people with disabilities are "qualify[ing]" for such elimination, on the basis that their lives lack meaning or quality. This section examines several recent cases affecting people with disabilities to demonstrate the trend of justifying death by using quality-of-life language. These cases generally involve two different scenarios. In one situation, a severely physically disabled person asserts his right as a competent¹¹⁸ adult to refuse life-sustaining treatment. In the other situation, a family member or hospital requests court permission to withhold or withdraw life-sustaining treatment from a person with severe mental disabilities.¹¹⁹ In both situations, nontreatment or discontinuation of treatment is based on the premise that the individuals' disabilities have diminished the quality of their lives to the point that death is preferable to life.

1. *Competent Adults with Disabilities*

When adults with severe disabilities assert their right as competent adults to refuse medical treatment, courts will generally apply a balancing test, weighing the individual and state interests.¹²⁰ The individual's interests are self-determination and the right to refuse medical treatment.¹²¹ The state's interests are generally comprised of four elements: (1) preserving the sanctity of life; (2) preventing suicide; (3) protecting innocent third persons; and (4) preserving the integrity of the medical profession.¹²² At least one court has added a fifth element: encouraging humane care of people with disabilities requiring life-sustaining treatment.¹²³

118. Establishing and implementing appropriate guidelines for determining competency is a very difficult task "The search for a unitary test of competency is, in the words of Dr. Loren Roth, a 'search for a Holy Grail.'" Michael L. Perlin, *Competency Deinstitutionalization and Homelessness: A Story of Marginalization*, 28 HOUS. L. REV. 63, 113 (1991), (quoting Loren H. Roth, et al., *Tests of Competency to Consent to Treatment* 134 AM. J. PSYCHIATRY 279, 283 (1977) (discussing five basic types of competency tests including: "1) evidencing a choice, 2) 'reasonable' outcome of choice, 3) choice based on 'rational' reasons, 4) ability to understand and 5) actual understanding")). See also 1 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN BIOMEDICAL AND BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS 47 (1982) (asserting that "any determination of the capacity to decide on a course of treatment must related to the individual abilities of a patient the requirement of the tasks at hand and the consequences likely to flow from the decision"). According to the Commission, capacity for decisionmaking requires that the individual have a set of values, the ability to comprehend and communicate information and the ability to "reason and to deliberate about one's choices."

119. See *infra* notes 157-86.

120. See *In re Quinlan*, 355 A.2d 647, 667-63 (N.J.), cert. denied, 429 U.S. 922 (1976) (holding that state interests of preservation of life and maintenance of the integrity of the medical profession must be weighed against the individual's right of privacy found in the Fourteenth Amendment).

121. See *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 277 (1990) (holding that the individual's right to refuse medical treatment is founded in fourteenth amendment liberty interest).

122. See *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1977); *McKay v. Bergstedt*, 801 P.2d 617, 621-22 (Nev. 1990); cf. *In re Guardianship of Browning*, 543 So. 2d 266 n.11 (Fla. Dist Ct. App. 1989) (suggesting that additional state interests could be considered).

123. *McKay v. Bergstedt*, 801 P.2d at 621-22.

The first major case to address the right to die for a competent adult with severe physical disabilities was *Bouvia v. Superior Court*.¹²⁴ Elizabeth Bouvia, a twenty-eight year-old college educated woman with severe cerebral palsy, filed a petition requesting injunction to force doctors to remove her feeding tube.¹²⁵ In the three years preceding her suit, Ms. Bouvia suffered tremendous personal loss. After entering graduate school, her dean informed her that regardless of her academic success, she could not expect job placement.¹²⁶ Her placement office informed her that if the university had known of her severe disabilities, they would not have accepted her into the graduate program in the first place.¹²⁷ When she dropped out of school, the state of California repossessed her accessible van.¹²⁸ She also needed surgery to relieve severe spasticity in her arms, but MediCal refused to provide the necessary funding.¹²⁹ Shortly after these events, she miscarried her child and her husband left her. Although she had temporarily moved in with her father, she was forced to find alternative housing because her father could not provide adequate care.¹³⁰

After many unsuccessful attempts to find a residence with suitable personal assistive services, she checked into a public hospital and requested to die. A trial court refused to grant permission, and her friends assisted her in finding other temporary housing. Her continued attempts to find a permanent independent living situation were unsuccessful, however, and she returned to a hospital intending to starve herself to death. Her attempts to die were again thwarted when doctors inserted a feeding tube to provide her with necessary nutritional support. She petitioned the court, requesting an order to remove the tube and to enjoin the doctors from additional attempts to maintain her life.¹³¹

The trial court again denied her request, but this ruling was overturned by the appellate court.¹³² The appellate court justified its reversal by determining that Bouvia's life was devoid of any quality.¹³³ It defined her life in incredibly negative terms and presented her request as entirely rational in light of her physical condition.¹³⁴ The court sympathetically asked: "Can anyone blame her if she wants to fold her cards and say 'I'm out'?"¹³⁵

The recent life stresses Bouvia experienced would, in any other case, cause a court to characterize her request as a suicide request, triggered by suicidal

124. 225 Cal. Rptr. 297 (Cal. Ct. App. 1986).

125. *Id.*

126. Mary Jane Owen, *The Goose Girl*, THE DISABILITY RAG, Feb./Mar. 1984, at 1.

127. *Missing Pieces*, THE DISABILITY RAG, Feb./Mar. 1984 6, at 6.

128. Owen, *supra* note 126, at 4.

129. *Missing Pieces*, *supra* note 127, at 5-6. MediCal ruled that the surgery was experimental. *Id.*

130. Owen, *supra* note 126, at 1.

131. *Id.*

132. *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986).

133. *Id.* at 305.

134. *Id.*

135. *Id.* at 307.

depression. Yet, the court failed to consider these life-shattering events; it was too intently focused on her physical condition and lack of independence.

Petitioner's physical handicaps of palsy and quadriplegia have progressed to the point where she is completely bedridden. Except for a few fingers of one hand and some slight head and facial movements, she is immobile. She is physically helpless and wholly unable to care for herself. She is totally dependent upon others for all of her needs. . . .

Here, if force fed petitioner would have to be fed, cleaned, turned, bedded, toileted by others for 15 to 20 years! . . . Although alert, bright, sensitive, perhaps even brave and feisty, she must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness. . . . We cannot conceive it to be the policy of this State *to inflict such an ordeal* upon anyone.¹³⁶

Based on this assessment of the quality of Bouvia's life, the court granted her petition and ordered the trial court to grant the requested injunction.¹³⁷ The court, in finding for Bouvia, clearly considered her life as totally lacking an acceptable quality-of-life. Rather than focus on the fact that Bouvia checked into the hospital after three years of incredible emotional stress caused at least in part, by her homelessness, the court focused solely on her severe physical disabilities and her dependence on others to find that her life was just not worth living.¹³⁸

Kenneth McKay's life (and death) demonstrates that other courts have displayed a similarly distorted view of people with severe physical disabilities. McKay became paralyzed in a swimming accident when he was ten. Due to his quadriplegia, McKay was dependent on a ventilator and required personal assistive services. He had continuously resided with his father since the accident. When McKay was thirty-one, his father became terminally ill. McKay petitioned the court for an order directing the removal of his ventilator. The trial court granted his request and the Nevada Supreme Court affirmed.¹³⁹

The supreme court classified McKay as a non-terminal, competent adult,¹⁴⁰ and balanced his right to refuse medical treatment against the state's interests. The court re-framed McKay's interest in the right to refuse medical treatment¹⁴¹ as "the interest . . . in determining the extent to which

136. *Id.* 299, 305 (emphasis added).

137. *Id.* at 307. Now thirty-five, Bouvia lives in the Los Angeles County-USC Medical Center. She continues to assert her desire to die, but fears that the process of starvation will be too painful. "I've never changed my mind but it's kind of a Catch-22 situation.' Now that she has the right to starve herself to death she says, she couldn't stand the pain and 'it's not like the doctors are going to help me.'" Beverly Heyette, *The Reluctant Survivor: 9 Years After Helping Her Fight to the Right to Die, Elizabeth Bouvia's Lawyer and Confidante Killed Himself—Leaving Her Shaken and Living the Life She Dreaded*, L.A. TIMES, Sept. 13, 1992, at E2. She states, however, that her physical condition has improved and her pain is managed with morphine. *Id.*

138. *Bouvia v. Superior Court*, 225 Cal. Rptr. at 138.

139. *McKay v. Bergstedt*, 801 P.2d 617 (Nev. 1990). McKay died before the opinion was written but the court retained the case because it addressed an important public issue. *Id.*

140. *Id.* at 620

141. *Id.* at 621. "[W]e do agree with the United States Supreme Court . . . that a person's

he . . . is willing to have a devastated life continued artificially or by radical medical treatment."¹⁴² The court then considered the state's interests. (1) preserving the sanctity of life; (2) preventing suicide; (3) protecting innocent third persons who could be adversely affected by the individual's death; (4) preserving the integrity of the medical profession; and (5) encouraging charitable and humane care of people with disabilities requiring life-sustaining treatment.¹⁴³

According to the court, the state's fundamental and compelling interest in preserving life depreciates as the individual's quality-of-life diminishes:

[A]t some point in the life of a competent adult patient, the present or prospective quality of life may be so dismal that the right of the individual to refuse treatment or elect a discontinuance of artificial life support must prevail over the interest of the State in preserving life We therefore conclude that in situations involving adults who are: (1) competent; (2) irreversibly sustained or subject to being sustained by artificial life support systems or some form of heroic, radical medical treatment, and (3) enduring physical and mental pain and suffering, the individual's right to decide will generally outweigh the State's interest in preserving life.¹⁴⁴

The court held that McKay fell within that situation. Even though he had completed school, could operate a computer and wheelchair on a limited basis, and otherwise live "a useful and productive life," this was deemed insignificant in light of his quadriplegia, which required the use of a ventilator and personal assistive services.¹⁴⁵

Several aspects of this decision are troubling. While McKay met the first criteria, he arguably did not meet the other ones. The ventilator, characterized as radical treatment, had been in place for over twenty years, since the accident. Characterizing such supports as radical justifies a diminished interest in the lives of many people with disabilities, especially people with severe disabilities. Supports such as wheelchairs, electronic monitoring devices, shunts, and ventilators are necessary to the lives of many disabled people and should hardly be considered radical or heroic.¹⁴⁶ McKay arguably failed to meet the third requirement also. While he appeared to be suffering much mental pain, evidence strongly indicated that his suffering was due in large part to his fear that he would not receive adequate personal assistive support after his father died. The court recognized that "fear of the unknown is a common travail even among those of us who are not imprisoned by paralysis and a total dependency upon others,"¹⁴⁷ and admitted that pro-

liberty interest is fundamental constitutional value implicated in 'right to die' cases." *Id.* (citing *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 277 (1990)).

142. *McKay*, 801 P.2d at 1621. Although the court initially described McKay as "nonterminal," it justified its articulation of his individual interest "[b]ecause many individuals find themselves facing a *terminal* condition susceptible to indefinite suspension by medical intervention." *Id.* (emphasis added).

143. *Id.*

144. *Id.* at 622-24.

145. *Id.*

146. *McKay*, 801 P.2d at 634-35 (J. Springer, dissenting).

147. *Id.* at 624.

viding humane care is a vital state interest.¹⁴⁸ Surely the state's interest in McKay's life should have been aimed at relieving the problems caused by inadequate personal assistive care for him (and other people with disabilities), rather than justifying his fears. Instead, the court held McKay's decision was rational in light of his disabilities (and, presumably, the state's inadequate support services).

The state's second interest, preventing suicide, was similarly dismissed. The court acknowledged that McKay was requesting the right to affirmatively hasten his death and that had McKay not been disabled, his liberty interest would not outweigh the state's interest: "Our societal regard for the value of an individual life . . . would *never* countenance an assertion of liberty over life under such circumstances."¹⁴⁹ The court then justified a diminished "regard for the value of" McKay's life by examining his motive, in light of his physical condition. According to the court, the motives behind a person's request to die should be considered in light of their quality-of-life. "If a competent adult is beset with an irreversible condition such as quadriplegia, where life must be sustained artificially and under circumstances of total dependence, the adult's attitude or motive *may be presumed not to be suicidal*."¹⁵⁰ In other words, the desire to die is entirely rational for a person with severe physical disabilities. McKay did not want to commit suicide; he merely wanted to be freed from his "paralytic prison from which there was no hope of release other than death."¹⁵¹ The state's duty to preserve the integrity of the medical profession and to prevent "selective destruction of lives deemed to have little utility"¹⁵² was not at issue because, according to the court, nontreatment is justified when treatment "will do little or nothing more than delay death in a bodily environment essentially bereft of quality."¹⁵³

The state's interest in encouraging appropriate support services for persons with disabilities, which offered the most hope for McKay, was barely given lip service. In a very disturbing observation, the court seemed to recognize that societal factors were the culprit causing McKay's diminished quality-of-life when it noted that McKay

was not without a meaningful life. His ability to give expression to his intellect by means of an orally operated computer, to learn, to enjoy reading . . . all reflected the possibility of a life imbued with a potential for significant quality and accomplishment . . . [McKay] needed some type of assurance that society would not cast him adrift in a sea of indifference after his father's passing."¹⁵⁴

How then, one must ask, could the court uphold his right to die rather than asserting his right to a minimal quality of life? Instead, the court merely

148. *Id.*

149. *Id.* at 625 (emphasis added).

150. *McKay*, 801 P.2d at 627 (emphasis added).

151. *Id.* at 626.

152. *Id.* at 626-27.

153. *Id.* at 628. The court also dismissed the third interest protecting innocent third parties because McKay had no dependents. *Id.* at 626.

154. *Id.* at 628.

held that this interest required the state to inform the disabled person of the available services provided by the government and other service organizations before he is permitted to kill himself.¹⁵⁵

The judicial reaction to both McKay and Bouvia because of their disabilities demonstrates how the new quality-of-life ethic devalues and excludes people with physical disabilities by concurring with them that death is better than life with severe disabilities, rather than by seeking to alleviate the pressures which make live with such disabilities so difficult.¹⁵⁶

2. *Incompetent Adults with Disabilities*¹⁵⁷

When an adult cannot and has never been able to communicate her wishes, courts generally use either the substituted judgment test or the best interests test. The substituted judgment test purports to focus on what the person would request were she able to communicate her preferences.¹⁵⁸ The best interest standard attempts to determine what course of action will be most beneficial to the individual.¹⁵⁹ Although courts frequently deny it, each standard incorporates the quality-of-life ethic into its decision-making process.

The first right-to-die case articulating the substituted judgment test was *Superintendent of Belchertown State School v. Saikewicz*.¹⁶⁰ Joseph Saikewicz, sixty-seven, had been institutionalized since childhood. He was physically healthy but unable to communicate verbally and was labeled severely mentally retarded. In 1976, doctors diagnosed him with acute myeloblastic monocytic leukemia, which was potentially curable with chemotherapy. Doctors, however, decided not to treat Saikewicz, and re-

155. *Id.* at 627. The court set up procedural guidelines for future cases where competent persons wish to exercise their right to refuse or withdraw medical treatment: (1) Two physicians besides the attending physician, must examine the person. They must certify in writing that: (a) he is mentally competent and understands the medical treatment options available and the consequences of not choosing the treatment options; (b) his condition is irreversible, or what improvements can reasonably be expected with medical treatment; (c) he is making the decision of his own free will; (d) if he is not terminal (i.e., will live more than six months), that he was informed of all the care options available through governmental and private services which could increase his quality of life.

If the preceding steps are taken and the person is terminally ill, his right to self-determination must be considered greater than the state interest and he may refuse or withdraw medical treatment. A physician who assists him in his attempt to end his life will be immune from civil and criminal liability. If the person is not terminally ill, a district court judge must balance his interests with the state interest. If the judge finds that the person's rights outweigh the state's interest, her determination will be final. If she determines that state interests override the person's interests, her decision is subject to appeal. In other words, a presumption in favor of permitting death has been established. If the person's right to die is sustained, an assisting physician will be immune from civil and criminal liability. *Id.* at 630.

156. See *infra* notes 238-45 and accompanying text.

157. "Incompetent" as used in this section refers to the legal determination that a person lacks the mental capacity to make informed medical decisions. See sources cited *supra* note 118.

158. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977). The decisions other people would make regarding treatment in a particular situation should have no direct bearing on the choice made for the individual in question.

159. *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985).

160. 370 N.E.2d 417 (Mass. 1977).

quested judicial approval of their decision.¹⁶¹

The trial court approved and the state supreme court affirmed its decision.¹⁶² According to the supreme court, the appropriate procedure to maintain integrity of a person determined incompetent is to ascertain what the individual would want.¹⁶³

[T]he decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.¹⁶⁴

Although the court recognized that no one could possibly determine what treatments Saikewicz would desire because he had never been able to express his wishes, it held that a surrogate could assert his (unknown) desires for him.¹⁶⁵ When the surrogate requested nontreatment, the court agreed, claiming its decision was based "on a regard for [Saikewicz's] actual . . . preferences."¹⁶⁶

Despite protests to the contrary,¹⁶⁷ the *Saikewicz* analysis was indeed based on quality-of-life considerations. As in the cases of Elizabeth Bouvia¹⁶⁸ and Kenneth McKay,¹⁶⁹ Saikewicz's life was described in negative terms with heavy emphasis on his alleged severe retardation.¹⁷⁰ The court

161. An appointed guardian ad litem concluded that in light of his mental retardation, which would presumably make him unable to understand what was going on, and the uncertain benefits, nontreatment was appropriate. *Saikewicz*, 370 N.E.2d at 419.

162. *Saikewicz*, 370 N.E.2d at 420. The trial court based its decision on a balancing test, weighing the benefits and burdens of the proposed treatment. According to the court, the benefits of the treatment were the possibility of lengthened life and that most people with his condition would desire the treatment. The burdens of the treatment included his age, his expected inability to cooperate, expected adverse side effects of chemotherapy, uncertain benefit of chemotherapy and the undesirable quality of his life even if chemotherapy was successful. *Id.*

163. *Id.* at 430, (citing John A. Robertson, *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, 75 COLUM. L. REV. 48, 63 (1976)).

164. *Saikewicz*, 370 N.E.2d at 431.

165. *Id.*

166. *Id.* at 432. The court held: "[f]inding no State interest sufficient to counterbalance a patient's decision to decline life-prolonging medical treatment in the circumstances of this case, we conclude that the patient's right to privacy and self-determination is entitled to enforcement." *Id.* at 435. *Saikewicz* and the substituted judgment standard has been severely criticized but is nevertheless still used. See Steven M. Richard, *Someone Make Up My Mind: The Troubling Right to Die Issues Presented by Incompetent Patients With no Prior Expression of a Treatment Preference*, 61 NOTRE DAME L. REV. 394 (1989) (rejecting standard because it permits the surrogate decision-maker to infuse personal prejudices); William A. Kraiss, Comment, *The Incompetent Developmentally Disabled Person's Right-to-Die Sterilization and Institutionalization*, 15 AM. J.L. & MED. 333 (1989) (rejecting standard because *inter alia*, it does not provide adequate accountability).

167. *Saikewicz*, 370 N.E.2d at 431. The court asserted that "the chance of a longer life carries the same weight for Saikewicz as for any other person, the value of life under the law having no relation to intelligence of social position." *Id.* "To the extent that this formulation equates the value of life with any measure of the quality of life, we firmly reject it." *Id.* at 432.

168. *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (1986). See *supra* notes 124-38 and accompanying text for discussion of this case.

169. *McKay v. Bergsedt*, 801 P.2d 617 (Nev. 1990). See *supra* notes 139-55 and accompanying text for discussion of this case.

170. As discussed previously, many people are inaccurately labelled mentally retarded. In-

explicitly required the decision-maker to take Saikewicz's mental ability into account when determining appropriate treatment. The primary reason for refusing treatment was that Saikewicz would not be able to comprehend what was happening to him, and would suffer short-term physical pain.¹⁷¹ Yet most courts would not consider nontreatment on this basis in the case of a small child who needed the treatment but was too immature to understand or cooperate.¹⁷²

The best interest test, on the other hand, focuses on which treatment alternative will provide the most benefit for the individual.¹⁷³ Courts have articulated the best interest standard in a variety of ways. In *In re Conroy*¹⁷⁴ the New Jersey Supreme Court established two tests. When the individual is incompetent and has never indicated her personal preference, the "pure-objective" test applies: Whether the burdens of continued existence "clearly and markedly" outweigh any benefits of life and continued treatment will result in "recurring, unavoidable and severe pain such that the effect of administering life-sustaining treatment would be inhumane."¹⁷⁵ When evidence that the individual would have refused treatment exists, such as declarations made while the person was competent, the "limited-objective" test applies: Whether the burdens of the person's continued life "markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life."¹⁷⁶ The court expressly denied that it was following a quality-of-life ethic,¹⁷⁷ yet stated that decision-makers should consider "level of functioning, [and] degree of humiliation and dependency" when making the treatment decision.¹⁷⁸ Each of these elements requires an analysis based on the quality-of-life ethic.

creasingly, as technology advances, we are discovering more and more people inaccurately labelled severely retarded who in fact were only unable to communicate through traditional means. See *supra* notes 60-65 and accompanying text.

171. *Saikewicz*, 370 N.E.2d at 421, 431.

172. The court apparently failed to consider whether sedatives or other calming techniques could be used, techniques which would almost certainly be utilized with a child. See Ira Mark Ellman, *Cruzan v. Harmon and the Dangerous Claim that Others Can Exercise an Incapacitated Patient's Right to Die*, 29 JURIMETRICS J., 389, 397 (1989).

173. See William A. Kraus, Note, *The Incompetent Developmentally Disabled Person's Right to Self-Determination: Right-To-Die, Sterilization and Institutionalization*, 15 AM. J.L. & MED. 333, 349 (1989).

174. 486 A.2d 1209 (N.J. 1985).

175. *Id.* at 1232.

176. *Id.*

177. *Id.* at 1232-33. The court stated:

[W]e expressly decline to authorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others. We do not believe that it would be appropriate for a court to designate a person with the authority to determine that someone else's life is not worth living because, to that person, the patient's "quality of life" or value to society seems negligible.

Id. The court limited its holding to cases involving elderly, incompetent residents of nursing homes with severe mental or physical disabilities and life expectancies of less than one year. *Id.* at 1230.

178. *Id.* at 1232. The court held that life expectancy prognosis, and treatment alternatives should also be taken into account. *Id.*

There are several other formulations. A New York court¹⁷⁹ established twelve factors to determine the best interests of an incompetent individual, including age, degree of pain and suffering, degree of disability and dependency, quality of life,¹⁸⁰ views of the individual's family members and physician, and type of care required if life is prolonged.¹⁸¹ In 1983, the President's Commission on the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission), also expressly advocated using the quality-of-life ethic to determine the best interests of the individual.¹⁸² According to the President's Commission, the decision-maker should consider "such factors as the relief of suffering, the preservation or restoration of function, and the quality as well as the extent of life sustained."¹⁸³

All of these standards, therefore, expressly or implicitly devalue a person's life on the basis of mental disability or physical dependency. If the decision-maker determines that life with severe mental disabilities is undesirable, or that being physically dependent is undesirable, nontreatment can be justified.¹⁸⁴ In light of the historical devaluation of severely disabled person's lives¹⁸⁵ and increasing awareness of the possibility of inaccurate assessments,¹⁸⁶ reliance on level of mental ability is especially dangerous.

III. QUALITY-OF-LIFE AND OTHER DECISION-MAKING MODELS

Part II examined how the judicial application of the quality-of-life ethic invariably leads to detrimental decisions regarding the lives of severely disabled persons. There are other decision-making models which give rise to the same concerns. This section will address how parents, doctors, and hospital ethics committees can also succumb to the quality-of-life ethic when making treatment decisions.

179. *In re Beth Israel Medical Center*, 519 N.Y.S.2d 511, 517 (N.Y. App. Div. 1987).

180. The court defined quality of life as the "extent, if any, of pleasure, emotional enjoyment, or intellectual satisfaction." *Id.*

181. *Id.* Other factors were life expectancy, risks of treatment, previous preference, the individual's religious views, and whether the state has any overriding interest in sustaining life. *Id.*

182. PRESIDENT'S COMM'N ON THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FORGO LIFE SUSTAINING TREATMENT: ETHICAL, MEDICAL AND LEGAL ISSUES IN TREATMENT DECISIONS* 134 (1983).

183. *Id.* at 135. The commission also advocates considering what impact the decision will have on the individual's family. *Id.* at 136.

184. Level of functioning, degree of humiliation and dependency are factors under *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985). Degree of disability and dependency and extent of intellectual satisfaction are factors under *In re Beth Israel Medical Center*, 519 N.Y.S.2d at 517.

185. See Gerry & McWhorter, *supra* note 26, at 496 (asserting that United States policy towards people with severe disabilities has historically been based on three principles: dehumanization, inferior social and legal status and mandatory segregation). For an extensive discourse on disability discrimination imbedded in our society and legal system, see MARTHA MINOW, *MAKING ALL THE DIFFERENCE, INCLUSION AND EXCLUSION AND AMERICAN LAW* (1990).

186. See *supra* notes 60-65 and accompanying text.

When an individual is a minor or considered incompetent,¹⁸⁷ a presumption generally exists that the family should make treatment decisions for the individual.¹⁸⁸ Family members presumably know the individual best and will be most protective of the individual's interests. In the case of minors, parental autonomy is a fundamental right, protected by the privacy right found in the Fourteenth Amendment.¹⁸⁹ "[T]he custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder."¹⁹⁰ There are several dangers, however, in relying solely on parental decisions. Parents are just as susceptible to the quality-of-life ethic. In the case of newborns, the shock and grief of an unexpected serious disability can affect parents' competence to make appropriate decisions. Parents may be extremely susceptible to external pressures and may not understand much of the medical information provided to them in a crisis situation.¹⁹¹ Parents may experience a conflict of interest between their desires and the best interests of the child. They may have internal biases concerning disabled people resulting from previous personal experiences.¹⁹² Therefore, parental autonomy cannot be absolute.¹⁹³

Doctors are arguably best equipped to understand medical treatment and medical implications of a disability. Thus, their participation in the decision-making process is invaluable; however, serious difficulties arise with physicians assuming the prominent role in the decision-making process. Doctor recommendations are too often clouded by their own negative attitude towards disabled people. There are countless cases where doctors have made dire predictions concerning newborns which turned out to be completely inaccurate. For example, doctors diagnosed Sondra Diamond with

187. See *supra* note 157 for definition of incompetent.

188. See BUCHANAN & BROCK, *supra* note 11, at 136.

189. See *United States v. Orita*, 413 U.S. 139, 142 (1973) (privacy right includes right of marriage, procreation, motherhood, child rearing, and education); *Wisconsin v. Yoder*, 406 U.S. 205, 232 (1972) (privacy right protects parental right to determine child's religious upbringing); *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925) (liberty of parents to direct education of children); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (liberty of parents to raise child).

190. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944). This right, however, is not absolute. In the case of minors, the state has a duty, as *parens patriae*, to protect children, and may intervene in family decisions in order to protect the child's health. *In re Phillip B.*, 156 Cal. Rptr. 48, 50 (1979), *cert. denied*, 445 U.S. 49 (1980).

191. See Siegfried M. Pueschel, *Ethical Considerations in the Life of a Child with Downs Syndrome*, 5 ISSUES IN LAW & MED. 87, 94 (1989); see also *infra* notes 195-99 (discussing how physicians may present diagnosis to advance their treatment recommendations).

192. See Robyn S. Shapiro & Richard Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827, 835 (1986).

193. Courts have set forth several elements to consider in judicial review of parental decisions regarding treatment of a child including the severity of harm the child is currently suffering or will suffer, the medical evaluation of the proposed treatment, the risks of the treatment and, if possible, the child's expressed preferences. See *In re Phillip B.*, 156 Cal. Rptr. 48, 50 (1979), *cert. denied*, 445 U.S. 49 (1980). "Of course, the underlying consideration is the child's welfare and whether his best interests will be served by the medical treatment." *Id.*; see also, Martha Minow, *Beyond State Intervention in the Family: For Baby Jane Doe*, 18 U. MICH. J. L. REF. 993 (1985) (discussing tensions between family privacy and state intervention and offering a constructive framework for resolving the conflicts).

cerebral palsy at birth, and predicted that she had little or no chance of achieving any type of meaningful life. She successfully attended college.¹⁹⁴ When Sondra suffered serious burns as an adult, doctors recommended non-treatment on the basis of their perception of her severe disability which prevented "normal" life. She had to fight to receive necessary medical treatment.¹⁹⁵ The Oklahoma Experiment¹⁹⁶ also illustrates the danger posed when physicians present information to parents in order to advance the physicians' recommendations. There, Dr. Gross, lead physician, acknowledged that newborns "considered to have a poor prognosis have a survival equal to that of babies with a good prognosis, if they receive early surgical treatment" yet the doctors presented prognoses in ways which advanced their recommended outcomes.¹⁹⁷ The Indiana Baby Doe case provides yet another illustration. Dr. Walter Owens, Baby Doe's attending physician, explained that his personal experience with a disabled child strongly influenced his recommendation not to treat Baby Doe. His nephew's child was born with a birth defect, presumably Down's Syndrome, and required major surgery. Dr. Owens described this child: "It learned to walk at the age of four, and it has never learned to talk. . . . Obviously, this has colored my thinking on the survival of such children. I believe there are things that are worse than having a child die. And one of them is that it might live."¹⁹⁸

Hospital ethics committees have been offered as a mechanism to facilitate medical treatment decisions.¹⁹⁹ Ethics committees can serve several functions. They can provide education on bioethical issues and be a forum for arbitrating disputes concerning care. Further, if properly composed of an interdisciplinary team, they can serve to facilitate principled medical decision-making.²⁰⁰ History demonstrates, however, that ethics committees are

194. See "I Am Not What You See," A Film Dialogue Between Sandra Diamond and Roy Bonisteel, reprinted in Judith Areen et al., *LAW, SCIENCE, & MEDICINE* 1199, 1202 (1984).

195. *Id.*

196. See *Early Management*, *supra* note 68. Even when prognoses are not purposely slanted, the potential for inaccurate prognoses is most acute in the case of newborns and young children with disabilities. Intellectual capacity is highly unpredictable in the first stages of life. Further, it is virtually impossible to accurately predict the long-term benefits of medical treatment given to babies born with disabilities.

197. See Gross, *Newborns*, *supra* note 68, at 1633.

198. LYON, *supra* note 7, at 27. The Royal Dutch Society recently called for the use of an "unlivable life" prognosis, based on the doctor's personal experience, intuition, and available statistics relating to the specific condition of the child. The society defends withholding of treatment and active killing of a child who receives an unlivable life prognosis. In cases of uncertain prognosis, the report recommends that doctors keep the patient alive "provided that the . . . physician is willing to forgo life-supporting measures and possibly terminate the patient's life if the final prognosis appears to be an 'unlivable life'." *Report of The Royal Dutch Society of Medicine on "Life-Termination Actions with Incompetent Patients, Part I: Severely Handicapped Newborns*, 7 *ISSUES IN LAW & MED.* 365, 366 (1991).

199. See BUCHANAN & BROCK, *supra* note 11 at 148. For an in-depth look into the experiences of one hospital's ethics committee, see Shapiro & Barthel, *supra* note 185. See also sources cited at *supra* note 103 (discussing benefits and dangers of ethics committees).

200. *Id.* at 149.

no guarantor of safety for people with disabilities.²⁰¹ During the eugenics movement in the early 1900s, ethics committees were established to regulate sterilization of people with disabilities provided scant protection. Similarly, in pre-World War II Germany, ethics committees required to review euthanasia cases invariably recommended death for disabled people.²⁰²

A more recent situation, set forth in *In re Jane Doe*,²⁰³ demonstrates how hospital committees may attempt to coerce a nontreatment decision over family objections. Jane Doe was diagnosed with an unknown neurological degenerative disorder at thirteen.²⁰⁴ Her condition was described as vacillating between a deep stupor and a slight coma. The treating hospital, asserting that continued medical treatment constituted medical abuse, petitioned the court to authorize withdrawal of life-support systems against the wishes of the teenager's father.²⁰⁵ Therefore, even ethics committees are prone to follow the quality-of-life ethic which has such a negative impact on disabled people.

IV. DILEMMAS WITH DIAGNOSES & DEFINITIONS

As the previous sections illustrated, when courts, parents, doctors, or hospital ethics committees apply the quality-of-life ethic, their negative attitudes towards people with severe disabilities too often result in decisions to forego or withdraw necessary medical treatment. This section will illustrate the problems with flawed medical diagnoses, which render quality-of-life determinations based on these diagnoses especially problematic. Compounding this problem, definitions are easy to manipulate. By redefining disease, disability, treatment and personhood based on the quality-of-life ethic, courts and other decisionmakers can too easily justify their decisions to permit the nontreatment — death — of persons with severe disabilities.

A. UNCERTAIN DIAGNOSES

Many of the court cases applying the quality-of-life ethic have involved individuals diagnosed as being in a persistent vegetative state (PVS). PVS is generally accepted as permanent, and decisions to provide or withhold treatment are often based on this diagnosis.²⁰⁶ Yet there are a number of cases

201. See GALLAGHER, *supra* note 7, at 82-84. Thirty states had legislation establishing sterilization procedures for the "feeble-minded and the hereditarily unfit." *Id.* at 82.

202. *Id.* at 56. See also Marker et al., *supra* note 2. Marker's article provides an interesting historical comparison between the eugenics and right to die movement in pre-World War II Germany and present day America.

203. *In re Jane Doe*, (Court Order, Civil Action No., D-93064 (Oct. 17, 1991), *quoted in Verbatim*, 7 ISSUES IN LAW & MED. 520.

204. *Id.*

205. *Id.* Her mother's wishes were not entirely clear. The court denied the hospital's request, holding: "Jane Doe may be dying, but she has yet to die, even under the broadest definition of that term. . . . To say that because her physicians have decided that there is no hope for 'meaningful recovery' life support should be removed comes close to imposing a duty to die on the terminally ill. This society does not impose such a duty[.]" *Id.*, *Verbatim* at 531.

206. Council on Scientific Affairs & Council on Ethical & Judicial Affairs, *Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support*, 263 AM. MED. ASS'N 426 (1990).

where the person was incorrectly diagnosed or the condition was not permanent. Further, although there is a generally accepted medical definition of PVS,²⁰⁷ courts use varying, inconsistent definitions. In *Cruzan v. Director, Missouri Department of Health*,²⁰⁸ for example, the Court defined PVS as "a condition in which a person exhibits motor reflexes but evinces no indications of *significant* cognitive function."²⁰⁹ Dr. Ronald Cranford, however, describes PVS as a condition where the person has no consciousness or interaction with the environment.²¹⁰

Christine Busalacchi's life further illustrates the ambiguity of PVS diagnosis and the resulting dangers. Christine suffered a severe head trauma in an automobile accident in 1987.²¹¹ Six months after her accident, doctors diagnosed her condition as PVS, and a gastrostomy feeding tube was surgically implanted.²¹² In 1988, the Missouri Rehabilitation Center notified Christine's father that Christine would be discharged. He attempted to transfer her to a Minnesota hospital, so Dr. Ronald Cranford could evaluate her and recommend removal of her nutritional support.²¹³ The state intervened, however, requesting that the court permanently enjoin the father from ordering the removal of the feeding tube. State evidence indicated that Christine was not in a persistent vegetative state and that her PVS classification had been removed. Evidence demonstrated that Christine was interactive with her environment. She could sit up, eat orally, communicate with a

207. *Id.*

208. 497 U.S. 261 (1990).

209. *Id.* at 266 (emphasis added). This definition was also adopted in *In re Busalacchi*, 1991 WL 26851 (Mo. App. 1991). In 1991, the National Center for State Courts promulgated the Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment which listed the following definitional characteristics of PVS:

Basic Definition: Irreversible loss of all neocortical functions; brain stem functions intact.

Clinical Syndrome: Awake, but unaware; eyes open unconsciousness; sleep/wake cycles present; respirator independence.

Anatomic Substrate of Neurologic Damage: Varies, but most commonly extensive destruction of neocortex (hypoxic-ischemic encephalopathy) or subcortical white matter (head trauma).

Onset and Course: Sudden onset, secondary to hypoxic-ischemic insult or acute head trauma.

Prognosis for Survival in Terms of Cardio-Respiratory Functions; usually long-term, years or even decades.

Time When Prognosis for Recovery of Neurologic Functions can Be Determined with a High Degree of Certainty: Varies by cause; in hypoxic-ischemic encephalopathy, usually 1-3 months, in head trauma, usually 6-12 months.

Degree of Physical or Psychological Suffering: None.

NAT'L CTR. FOR ST. CT., GUIDELINES FOR STATE COURT DECISION MAKING IN AUTHORIZING OR WITHHOLDING LIFE-SUSTAINING MEDICAL TREATMENT (1991) (Appendix B). Consistent use of this definition would substantially limit inaccurate or inconsistent assessments.

210. Ronald E. Cranford, *The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)*, 18 HASTINGS CENTER REPORT, 27, 28 (Feb./Mar. 1988). This definition is contrary to the medical definitions, which requires that no cognitive function exist.

211. *In re Busalacchi*, No. 59582, 1991 WL 26851, at *1 (Mo. App. 1991).

212. *Id.* at 1.

213. *Id.* Cranford testified in *Cruzan v. Harmon*, that he will stop nutritional fluids on conscious patients who are severely mentally disabled. See Transcript, *Cruzan v. Harmon* (Cir. Dt. Jasper County, Mo. 1988) (No. CV 38-9P0, cited in 1991 Developments, *supra* note 52, at 417).

microswitch device, and laugh. Christine reacted to painful stimuli; she sometimes said "hi" with prompting; her eyes followed people in the room; and she smiled on occasion in response to auditory stimuli.²¹⁴ Although the court denied her father's right to move her, it repeatedly referred to her condition as being in a persistent vegetative state despite all the evidence to the contrary.²¹⁵

In early 1993, however, Mr. Busalacchi's request was granted when the state's case was dismissed.²¹⁶ Mr. Busalacchi promptly moved Christine to Barnes Hospital where neurologists diagnosed her condition as PVS,²¹⁷ a diagnosis in conflict with medical evidence. Employees at the Mount Vernon Rehabilitation Center assert that a video tape shows Christine smiling and jumping when startled, indicating that while undoubtedly severely brain damaged, Christine is conscious, aware of her surroundings and able to communicate on a very limited basis.²¹⁸

The neurologists' diagnosis, however, paves the way for her feeding tube to be disconnected. By the time this Comment is published, Christine probably will be dead. Tim Blair, spokesman for Barnes Hospital stated that "[a]s a major neuroscience center we routinely withdraw life support from profoundly impaired individuals based upon agreement between the family and the medical staff. What's best for the family is the guiding issue."²¹⁹ This, in spite of the fact that

Christine is not "dead;" she is not even sick. She is capable of taking her entire nutritional needs orally and was (according to court records) taking three meals a day by mouth. Her father, however, refused to allow her to continue to eat by mouth, so she is once again receiving nourishment through a feeding tube.²²⁰

An additional problem is that PVS, by definition, is considered permanent. Cases exist, however, where PVS patients have regained consciousness. In April 1989, for example, the following account was reported. An eighty-six year-old woman, after having a stroke, fell into a coma that lasted over four months. After diagnosing her condition as PVS, the woman's doctors sought and received judicial approval to remove her feeding tube. During the weekend following the court's approval, the woman awoke. Upon determining that she was alert, her doctor proceeded to describe her past medical and legal situation and asked her what she would have wanted done.

214. Report to the Probate Division Concerning the Status of Christine Busalacchi, An Incapacitated/Disabled Person, *In re Busalacchi*, No. 93799 (St. Louis County Cir. Ct. Feb. 4, 1991).

215. *In re Busalacchi*, No. 59482 1991 WL 26851 at 4 (Mar. 5, 1991).

216. Staci D. Kramer, *Right-to-Die Case Family Silent on Woman's Fate*, CHI. TRIB., Feb. 26, 1993, at N5.

217. *Id.*

218. *Doctors Say Woman Is in Persistent Vegetative State*, UPI, Feb. 25, 1993, available on LEXIS, Nexis Library, UPI File.

219. Staci D. Kramer, *Father Regains Control in Right-to-die Case*, CHI. TRIB., Feb. 20, 1993, at N2.

220. Mary Senander, *Keep on Fighting for the Life of Christine Busalacchi*, STAR TRIB., Feb. 2, 1993, at 9A.

"She replied, 'These are difficult decisions' and lapsed back into sleep."²²¹ In another situation, Jackie Cole suffered a massive brain hemorrhage and she fell into a coma. Doctors later diagnosed her condition as PVS and told her family this condition would last indefinitely.²²² Her family requested judicial approval to withdraw respirator support but the court stayed the decision. She woke up six days later and is now fully recovered.²²³

Diagnoses of other severe medical conditions are similarly suspect. The prognoses for many disabilities improve with advances in medicine. Therefore, disabilities previously considered severely debilitating are now less restrictive today.²²⁴ This "changeable meaning of particular [disabilities] offers reason to doubt that disabled people inevitably suffer great unhappiness and a lesser quality-of-life than others. . . . Therefore, advocates of the quality-of-life ethics run a serious risk of preserving old assumptions about the meaning of various disabilities."²²⁵

B. AMBIGUOUS DEFINITIONS

The situation is further complicated when conditions and diagnoses are defined by advocates on either side of the quality-of-life debate in order to enhance their case. "Every debater knows the importance of defining the terms used in the debate. If the vocabulary to be used can be manipulated to his advantage, the other side is almost sure to lose."²²⁶ For example, quality-of-life proponents may assert that it is unethical to use extraordinary means to artificially prolong the life of useless/severely disabled people who are a burden to themselves, their families and for society.²²⁷ Opponents of this ethic recharacterize the argument, asserting that it is unethical to discontinue food and water to save the life of people with severe mental and physical disabilities merely because they require assistance to participate in society. This lack of clear definitional guidelines renders any decision-making process useless because the situation at issue can be characterized according to any desired outcome. Consider the following situations.²²⁸ In 1984, a ninety-two year-old woman required surgery to reinsert her gastrostomy tube which had become dislodged.²²⁹ Her court-appointed guardian refused permission, however, and a Massachusetts court affirmed the guard-

221. The judge withdrew the order. See Sam Howe Verhovek, *New York Judge Revokes Right-to-Die Order as Patient in Coma Wakes*, N.Y. TIMES, Apr. 13, 1989, at B3.

222. Nancy Gibbs, *Love and Let Die*, TIME, Mar. 19, 1990, at 62, 70.

223. *Id.* She still suffers some memory loss. There are additional documented cases of people regaining consciousness after a PVS diagnosis. See BUCHANAN & BROCK, *supra* note 11, at 131 (citing cases of partial recovery).

224. For example, a new inner-cochlea hearing aid can now allow a profoundly deaf person to hear. Scientists are developing electronic devices to help people with paralysis walk. Communication devices are enabling persons with speech and physical disabilities to communicate. See *supra* note 65.

225. MINOW, *supra* note 185, at 320.

226. Albert E. Gunn, *The Soft Underbelly of Patient Autonomy*, 7 ISSUES IN L. & MED. 147 (1991).

227. See text accompanying *supra* note 48.

228. The irony of the two situations was noted in Marker, et al., *supra* note 2, at 281.

229. *In re Hier*, 464 N.E.2d 959 (Mass. 1984).

ian's position. According to the court, the gastrostomy was a "major surgical procedure," which was "highly intrusive" and carried a "high risk."²³⁰ At the same time, another ninety-four year-old woman in Massachusetts required the same surgery. After she received the necessary gastrostomy tube, her doctors characterized her surgery as "minor stomach surgery" to "maintain adequate nutrition."²³¹ Why were the two women treated so differently? The person who was refused life saving treatment was Mary Hier, an institutionalized woman with dementia (she believed she was the Queen of England). The woman who received the necessary surgery was Rose Kennedy.

In a 1990 case, the Illinois Supreme Court set a frightening precedent when it permitted the withdrawal of food and water from a seventy-six-year-old man by redefining terminal illness.²³² Mr. Greenspan was diagnosed with an organic brain disease in 1983. In 1984, a stroke left him severely brain damaged.²³³ The trial court refused his guardian's request to discontinue treatment because an Illinois law prohibited withdrawal of food and water in cases where "withholding would result in death solely from the dehydration or starvation, rather than from the existing terminal conditions."²³⁴

The supreme court reversed, holding that, in Greenspan's case, food and water could be withheld because:

Mr. Greenspan is terminally ill in the sense that his illness would have been terminal if current means of keeping him alive were unavailable. If Mr. Greenspan's artificial food and water were discontinued by removal of his feeding tube, he would die within a week at most. Such death would result from the combination of his terminal condition generally and one of its specific results, his inability to swallow.²³⁵

This holding raises major implications for people with severe disabilities. Modern medicine has provided shunts, pace makers, and transplants. To hold that someone who needs modern technology for life-saving or life-sustaining treatment is terminally ill is to classify most, if not all, severely disabled people as terminal. Under this classification, medical treatment and food and water could be withheld from Kenneth McKay and Elizabeth Bouvia as well as most, if not all, infants born with disabilities — any person who requires modern technology to maintain their life could be classified as terminally ill and refused medical treatment.

Another troubling aspect for severely disabled people is the holding by the court that Greenspan's inability to eat, not the removal of nutritional sup-

230. *Id.* at 964.

231. *Rose Kennedy Doing Fine, Says Doctor*, BOSTON GLOBE, Jul. 30, 1984 at 35.

232. *In re Estate of Greenspan*, 558 N.E.2d 1194 (Ill. 1990).

233. Medical evidence indicated that Greenspan had been in a chronic vegetative state for five years. As the dissent noted, however, Greenspan could eat orally. *Id.* at 1207 (J. Ward, dissenting). Even if Greenspan was accurately diagnosed, the court's analysis, which redefined disability as a terminal illness, is faulty.

234. *Id.* at 1198-99.

235. *Id.* at 1196.

port, would be the cause of his death.²³⁶ First, as the dissent pointed out, Greenspan's feeding tube was inserted to increase convenience, not because he could not swallow.²³⁷ Second, this description could open the door to justify any nontreatment decision. Under this description, inability to independently eat, rather than failure to feed would be the cause of an infant's death. Antibiotic medication could be withheld from an accident victim on the ground that an infection killed him, not lack of treatment. Such a description is both medically and ethically unsound.

V. CONCLUSION: QUALITY OF LIFE MATTERS

Quality-of-life inquiries should examine what makes life worth living for people, and should work to provide a worthwhile quality-of-life to all people. In the case of people with disabilities, rather than assuming that life lacks quality due to disability, decision-makers should question "whether the apparent misery is the result of a lack of adequate support services for the person. If, as is more likely, the issue is one of inadequate support services, the answer is clearly to demand that those services be provided."²³⁸ The voice of people with disabilities echos this:

Many are wondering why society is so quick to assist a disabled person who wants to end life when the same desire to die in an able-bodied person is viewed as a genuine cry for help. It is the fear of no support to live independent lives, not their disabilities, that drives people with disabilities to end their lives.²³⁹

This Comment has demonstrated why the current quality-of-life ethic must not be a basis for denying medical treatment to people with severe disabilities. Focusing primarily on the disabilities of people, this ethic embraces the assumption that society was created for "normal" people, and injustice is merely an unavoidable consequence of defects in the disabled individual.²⁴⁰ Thus, it can be used to categorically exclude entire groups of

236. *Id.* at 1201.

237. *In re Estate of Greenspan*, 558 N.E.2d at 1207 (J. Ward, dissenting).

238. Redfern Legal Center, *Lives of Great Value* (Oct. 31, 1989), *quoted in* Christopher Newell, *Lives of Inestimable Value: Life Worthy of Life*, 7 ISSUES IN L. & MED. 245, 251 (1991).

239. National Legal Center Staff, *Medical Treatment for Older Persons and Persons with Disabilities: 1990 Developments*, 6 ISSUES IN LAW & MED. 341, 349 (1991) (citing Coleman, *Growing Support of the "Right to Die": A Worrisome Trend*, NASHVILLE BANNER, May 10, 1990, at A19).

240. Professor Martha Minow refers to the problems inherent in the exclusionary quality-of-life ethic as the dilemma of difference. MINOW, *supra* note 185, at 20. The perception that disparate treatment of severely disabled people is permissible or even necessary is inherent in virtually all public policy decisions concerning people with severe disabilities. Minow articulates five assumptions that generally drive decisions based on disability (or other difference): Rather than viewing the characteristic in question as a comparison between an excluded individual and some norm established by the decision-makers in power, one assumes that the difference is in the individual. *Id.* at 51, 53-56. An unstated point of reference is adopted when assessing the different individual and determining that special treatment is warranted. This point of reference is assumed to be neutral and natural. For example, special treatment, "when used to describe pregnancy or maternity leave, posits men as the norm and women as different or deviant from that norm." *Id.* at 58. Because the differences are assumed to be intrinsic, and the norm neutral, the decision-maker assumes that he can make impartial deter-

people, based on a disability label, from the benefits of life.

The quality-of-life ethic should instead, return to its traditional use to promote improvements in the quality of severely disabled peoples' lives.²⁴¹ Basic life necessities such as housing should be addressed. For example, rather than devaluing a severely disabled woman's life because she is homeless or institutionalized, efforts to improve her quality-of-life should be made by providing her an opportunity to live in the community. Numerous demonstration projects across the country have proved that even the most severely disabled individual can live in the community and be provided the necessary support.²⁴² Education should be also addressed. Rather than devaluing a boy's life because he is severely disabled, efforts to improve the quality of his life should include providing an appropriate education. School districts throughout the United States are demonstrating that all children can learn in inclusive settings.²⁴³ Our quality-of-life ethic should, in other words, be based on the assumption that people with severe disabilities are "whole people, not defective collections of body parts, intellect, and genes which are inherently less capable and worthy of life than so-called able-bodied people,

minations, unbiased by any personal perspective. *Id.* at 52, 60-65. The assumed intrinsic difference and neutral norm also negates any value in the perspective of the different person. *Id.* at 52, 66-70. The current state of society is natural, neutral and desirable. *Id.* at 53, 70-73.

Minow urges decision-makers to make policy decisions with the recognition that difference determinations are comparative:

If we identify the unstated points of comparison necessary to the idea of difference, we will then examine the relationships between people who have and people who lack the power to assign the label of different. If we explore the environmental context that makes some trait stand out and some people seem not to fit in, we will have the opportunity to reconsider how and for what ends we construct and manage the environment. Then difference will no longer seem empirically discoverable, consisting of traits inherent in the "different person." Instead, perceptions of difference can become clues to broader problems of social policy and human responsibility.

Id. at 23.

241. See Aiken, *supra* note 24, at 18-21.

242. See Joyce Dawidczyk & Patricia Anderson, *Going Home and Other Adventures: A Guide to Supported Living for Persons with Disabilities*, (May 1992) (unpublished manuscript on file with author); Joyce Dawidczyk & Patricia Anderson, *Going Home: Final Recommendations for Development of Supported Living Services in Texas*, (Sept. 1992) (unpublished manuscript on file with author) (describing successful three-year supported living project and asserting that "all persons who have disabilities, including those with the most severe disabilities or the most significant support needs . . . can live alone or with others of their choice in their own home or shared homes when individualized appropriate supports are developed, accessed and maintained"); see also Jane A. Nesbit & Jay Klein, *New Hampshire's Home of Your Own* (Institute on Disability, University of New Hampshire 1991) (unpublished manuscript on file with author) (describing current project which facilitates consumer-controlled housing for individuals with severe disabilities in New Hampshire).

243. See DOROTHY KERZNER LIPSKY & ALAN GARTNER, *BEYOND SEPARATE EDUCATION: QUALITY EDUCATION FOR ALL* (1989); and *EDUCATING ALL STUDENTS IN THE MAINSTREAM OF REGULAR EDUCATION* (William Stainback et al. eds., 1989) (proposing educational reform to provide for quality, inclusive education for all students, including students with the most severe disabilities); see also, George Flynn, *A School System in Transition* (Waterloo Ontario, Canada, 1989) (unpublished manuscript on file with author) (recording how the Waterloo Region Roman Catholic School System was successfully restructured to provide education for all school children in a fully inclusive setting).

ple;"²⁴⁴ and we should question any ethic that "is prepared to fund the elimination and screening of people with disabilities, yet is not prepared adequately to fund the personal care and education services we need to lead autonomous, happy, and successful lives in the community."²⁴⁵

244. Christopher Newell for Disabled People's International (Australia) Limited, *Lives of Inestimable Value: Life Worthy to Life*, 7 ISSUES IN L. & MED. 251, 256 (1991).

245. *Id.*